

Interactive online survey raises awareness about cornea donation

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To cite: Tsigkos D, Tzelepi A, Kopsini D, *et al*. Interactive online survey raises awareness about cornea donation. *BMJ Open Ophthalmology* 2020;**5**:e000285. doi:10.1136/bmjophth-2019-000285

► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/bmjophth-2019-000285>).

Received 4 February 2019
Revised 2 December 2019
Accepted 1 January 2020

ABSTRACT

Objective To assess the impact of a 5 min interactive online survey on raising awareness about cornea donation and willingness to become a donor.

Methods An interactive online questionnaire was used to collect information regarding awareness, perceptions and attitudes towards cornea donation and to educate the participants about the process and value of cornea donation. Willingness to become a cornea donor was assessed at the beginning and the end of the survey.

Results The survey was completed by 1769 Greek residents. Willingness to become a cornea donor increased from 40.5% (n=717) at the beginning of the survey to 55.2% (n=977) by the end of it (p<0.00001). Younger participants, those whose work or studies were unrelated to the medical field, and those with the least knowledge about cornea donation and transplantation were more likely to change their views towards donation by the end of the survey (42.3%, 44.8% and 82.1% increase in willingness to donate, respectively). Major deterrents to donation were lack of information, concerns about the use of the donated corneas and corruption within the medical field.

Conclusion Our 5 min online survey had a significant impact on changing the mentality towards cornea donation in Greece. We live in an online era and incorporation of online tools and applications in awareness campaigns towards cornea and organ donation has become a necessity.

INTRODUCTION

Corneal blindness is the fourth leading cause of blindness worldwide.¹ It is the result of ocular infections, local and systemic degenerative and inflammatory disorders, and trauma. In contrast to other forms of blindness, corneal blindness is curable via corneal transplantation. With a 90%–95% success rate, corneal transplantation is the oldest, most common and most successful organ transplant operation to date.²

In Greece, a total of about 300 corneal transplantation surgeries are performed annually with corneal donor tissue that is imported at a cost that is prohibitive to many patients and/or the state (S. Palioura, personal communication with importing companies). According to the Global Survey of Cornea Transplantation

Key messages

What is already known about this subject?

► Greece, similar to most countries on a global scale, is not self-sufficient in corneal transplants. Thus, 75%–83% of its corneal grafts are imported at a prohibitive cost and cover only partially the national demand.

What are the new findings?

► A 5 min interactive online survey can have a significant impact on changing the mentality towards cornea donation, highlighting that knowledge correlates with willingness to donate.

How might these results change the focus of research or clinical practice?

► Educating the public using online tools can have a significant impact on raising willingness to become a cornea/organ donor.

and Eye Banking, the cornea procurement rate per capita is only 0.92×10^{-6} and Greece is classified as a non-sufficient country.³ About 50–75 grafts per year come from brain-dead multiorgan donors and the rest (about 225–250/year) are imported primarily from USA.

Though it is hard to estimate the actual annual need for corneal transplants in Greece, one may extrapolate from the well-documented need for cornea transplants in USA, a country that meets its local demands for transplants and exports the remaining tissue abroad. According to the 2017 Eye Banking Statistical Report by the Eye Bank Association of America, 50 934 transplantations were performed in the US population of 326 million. Respectively, in the Greek population of 107 million, the corneal transplant need would be about 1671 per year. Thus, the 300 corneal transplants done per year in Greece cover only 18% of the national annual need and 82% of the patients remain visually impaired, while the state is burdened with disability fees and productivity loss.



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Given the very low rate of cornea procurement per capita in Greece, we decided to assess the current beliefs of the Greeks towards cornea donation, and also to educate the participants on basic concepts (eg, what is cornea transplantation) and more advanced ones (eg, eligibility criteria for cornea donation, legislation regarding donation) using an interactive online questionnaire. A recent review of studies on awareness and attitudes towards cornea donation globally identified knowledge as the only modifiable factor associated with increased willingness to donate.⁴ Our goal was, thus, to explore whether lack of knowledge regarding cornea donation contributes to the low ratio of cornea procurement per capita and to see how dissemination of information aids in implementing a mentality shift for the sensitive, yet important, issue of organ donation.

MATERIALS AND METHODS

This study was conducted via an online semistructured questionnaire using the Google Form platform between 1 September 2016 and 15 April 2017.

Patients were not directly involved in the design of this study. The format of the questionnaire was based on previously published studies in the field of cornea and eye banking⁵⁻⁹ and included 20 questions on: (1) Demographic data (four items). (2) Knowledge regarding cornea transplantation (six items). (3) Knowledge regarding the eligibility and the process of cornea donation (four items). (4) Knowledge regarding the process and legislation for cornea donation in Greece (two items). (5) Willingness to become a donor (three items). (6) Barriers and incentives of cornea donation (two items). The questionnaire has been translated in English and is provided as a online supplementary data file. In contrast to previously published surveys, an informative page with photos and videos regarding the issues that were just assessed followed each set of questions. For example, questions concerning cornea transplantation were followed by images of cornea anatomy, corneal diseases, videos of the transplantation process as well as information regarding the donation process in Greece. The link to the online questionnaire was distributed through social media (eg, Facebook), in patient forums and through our participation in medical conferences in Greece. The test-retest reliability of the questionnaire was assessed in a pilot sample of 50 participants who answered the questionnaire twice within a short period of time, and it resulted in an acceptable Cronbach's α of 0.74. The educational material was omitted during the first administration of the questionnaire in this pilot group of participants. Thus, questions 19 and 20, which assessed the potential mentality shift towards becoming a cornea donor after the interactive educational survey were not included in the calculation of Cronbach's α .

All aspects of the study were conducted in accordance with the tenets of the Declaration of Helsinki. Statistical analysis was performed using the statistical

Table 1 Demographics of study participants

Demographics	
Gender	% (n)
Male	70.9% (1255)
Female	28.7% (507)
Other	0.4% (7)
Age, years	
<18	6.2% (109)
18-30	80.1% (1417)
31-45	9.4% (166)
46-60	3.5% (63)
>60	0.8% (14)
Profession/studies	
Non-medical	67.9% (1201)
Medical/dental/nursing students	23.7% (419)
Medical doctors (other than ophthalmologists)	3.9% (70)
Ophthalmologists	1.4 (25)
Other medical field professions (eg, nursing)	3.1% (54)

software SPSS v. 21.0 (IBM Corp, Armonk, New York, USA) and the χ^2 test was used to perform comparisons of categorical variables between the groups as per the central limit theorem.

RESULTS

The survey was completed by 1769 Greek residents. The demographic profile of the participants can be found in table 1.

Knowledge regarding cornea transplantation, the donation process and eligibility for cornea donation

Table 2 summarises participant responses regarding cornea transplantation, the donation process and eligibility for cornea donation. The majority of the participants (n=1365 or 77.2%) were aware that corneal diseases can lead to blindness, and 58.6% (n=1036) of them were familiar with the term 'cornea transplantation'. However, only 37.9% (n=671) knew that corneal blindness might be treatable with cornea transplantation. Moreover, only 32.7% (n=579) of the participants were aware that cornea transplantation surgeries are performed in Greece. Regarding cornea procurement, out of the 1769 participants, 23.7% (n=419) were unaware of cadaveric eye donation and thought that only heart-beating brain-dead donors are eligible to donate. A significant number of participants (13.4% or n=237) believed that the whole eye is removed, and 8.4% (n=148) of them believed that the appearance of the donor is affected significantly, and the funeral can only be done with a closed casket.

When asked about the annual need of cornea transplants in Greece, only 36.9% (n=652) answered correctly, while 53.0% (n=937) underestimated the number of

Table 2 Knowledge regarding cornea transplantation, the donation process and eligibility for cornea donation

Knowledge regarding cornea transplantation	Yes % (n)	No % (n)
Are you aware that some corneal diseases/conditions can lead to blindness?	77.2% (1365)	22.8% (404)
Are you familiar with the term 'cornea transplantation'?	58.6% (1036)	41.4% (733)
Are you aware that corneal blindness may be reversible with corneal transplantation?	37.9% (671)	62.1% (1098)
Are corneal transplantation surgeries performed in Greece?	32.7% (579)	67.3% (1190)
Knowledge regarding the donation process and eligibility for cornea donation	Yes % (n)	No % (n)
When a corneal graft is procured, is the whole eye removed?	13.4% (237)	86.6% (1532)
Does cornea donation change the appearance of the donor?	8.4% (148)	91.6% (1621)
Is cadaveric eye donation possible, or only heart-beating brain-dead donors are eligible to donate?	76.3% (1350)	23.7% (419)
Is it possible to donate only one's cornea and no other organs?	92.9% (1644)	7.1% (125)

transplants needed. There was considerable ambiguity among the participants regarding eligibility requirements for cornea donation. About a third of them (31.7% or n=561) replied that blood type compatibility was a requirement, 18.6% (n=329) of them thought that a chronic illness (eg, hypertension, diabetes) is a contraindication to donation and 2.5% (n=45) of them viewed wearing spectacles as another contraindication.

Considering the process of becoming a cornea donor, the vast majority of the participants (85.6% or n=1514) replied that it could be done by declaring it to the National Transplantation Organization in Greece via essentially an 'opt-in' system. Only 14.4% (n=255) of the participants were aware of the decisive role of the family as per the Greek legislation. Greece, along with other European countries such as Italy, Norway, Croatia and Bulgaria, has adopted a 'soft' opt-out system where the

family of the deceased plays a major role in the donation process (Greek law: 4075/2012).¹⁰

Willingness to donate

Willingness to donate was assessed in the beginning and at the end of the interactive questionnaire. In the beginning of our survey, 54.9% (n=971) of the participants replied that they already are or would like to become organ donors, 40.4% (n=715) were indecisive and 4.7% (n=83) answered that they are not interested in becoming organ donors. A similar pattern was observed when the participants were asked about eye/cornea donation, with 40.5% (n=717) saying yes, 53.0% (n=937) remaining indecisive and 6.5% (n=115) saying no. Willingness to become a cornea donor increased from 40.5% (n=717) at the beginning of the survey to 55.2% (n=977) by the end of it

Table 3 Willingness to become a donor at the beginning and at the end of the survey

	Positive at the start % (n)	Positive by the end % (n)	% Increase (95% CI)	OR (95% CI)	P value
Female	40.8% (513/1255)	57.0% (716/1255)	+39.6% (28.6% to 51.5%)	1.921 (1.640 to 2.252)	<0.00001
Male	39.4% (200/507)	50.9% (258/507)	+29.0% (+12.4% to 48.0%)	1.591 (1.240 to 2.040)	<0.001
<18 years old	22.0% (24/109)	37.6% (41/109)	+70.8% (+11.3% to 162.1%)	2.135 (1.176 to 3.876)	0.01
18–30 years old	38.4% (544/1417)	54.6% (774/1417)	+42.3% (+31.2% to 54.3%)	1.932 (1.663 to 2.244)	<0.00001
31–45 years old	55.4% (92/166)	61.4% (102/166)	+10.9% (–7.6% to +33.0%)	1.282 (0.828 to 1.985)	0.27
46–60 years old	71.4% (45/63)	77.8% (49/63)	+8.9% (–11.2% to +33.6%)	1.400 (0.625 to 3.138)	0.41
Profession/studies unrelated to medical field	36.2% (435/1201)	52.5% (630/1201)	+44.8% (+32.1% to 58.8%)	1.943 (1.650 to 2.288)	<0.0001
Profession/studies related to medical field	49.6% (282/568)	61.1% (347/568)	+23.1% (+10.7% to 36.8%)	1.592 (1.258 to 2.016)	<0.001
Total	40.6% (719/1769)	55.2% (978/1769)	+36.0% (+26.8% to 45.9%)	1.806 (1.580 to 2.063)	<0.00001

Percentile increase was calculated as: (final percentage–initial percentage)/initial percentage×100.

Table 4 Knowledge about cornea transplantation correlates positively with willingness to become a cornea donor

Aware about what the cornea is	Aware of corneal blindness	Aware that corneal blindness is reversible with cornea transplantation	Willingness to donate at the start of the survey % (n)	Willingness to donate at the end of the survey % (n)	% Increase of willingness at the end of the survey (95% CI)	OR (95% CI)	P value
No	No	No	25.0% (56/224)	45.5% (102/224)	+82.1% (+39.3% to 138.2%)	2.508 (1.680 to 3.745)	<0.0001
Yes	No	No	29.1% (44/151)	53.7% (81/151)	+84.1% (+37.8% to 145.9%)	2.814 (1.750 to 4.524)	<0.0001
Yes	Yes	No	32.2% (153/475)	50.7% (241/475)	+57.5% (+34.5% to 84.4%)	2.168 (1.666 to 2.821)	<0.0001
Yes	Yes	Yes	61.9% (309/498)	68.7% (342/498)	+10.7% (+1.1% to 21.2%)	1.341 (1.032 to 1.743)	0.028

(95% CI, 26.8% to 45.9%; $p < 0.00001$). (See [table 3](#), which highlights the rise in willingness to donate as it relates to sex, age and profession)

Regarding baseline knowledge, participants who were aware about what the cornea is, diseases leading to corneal blindness and its reversibility with cornea transplantation, were far more positive towards being future donors at the beginning of the survey (61.9%) compared with those who were less aware (25.0%, 29.1% and 32.2%, see [table 4](#)). Moreover, at the end of the survey participants with less prior knowledge on cornea donation and transplantation were more likely to change their mind and report that they would become eye donors. In particular, the percentile increase in willingness to donate was 82.1% ($p < 0.0001$), 84.1% ($p < 0.0001$) and 57.5% ($p < 0.0001$) for the initially less aware groups and only 10.7% ($p = 0.028$) for the more knowledgeable group ([table 4](#)). Finally, regardless of the prior knowledge status, willingness to become a cornea donor significantly increased from the beginning to the end of the survey ($p < 0.0001$ for the initially less informed groups, and $p = 0.028$ for the more informed one, see [table 4](#)).

Motives and deterrents to cornea donation

The motives of the participants as well as the deterrents towards cornea donation at the end of the survey are presented in relation to participant response at the start of the survey. The main motives of the 977 (55.2%) participants who were positive towards cornea donation at the end of the survey were the opportunity to give the gift of sight to a fellow citizen (54.1% or $n = 529$) and the nobility of the act of donation (40.5% or $n = 396$).

Among the 68 participants (3.8%) who were negative towards cornea donation at the end of the survey, the major deterrent was their belief that the body must remain intact after death (33.8% or $n = 23$). Other deterrents cited were corruption in the medical field (14.7% or $n = 10$), concerns about the use of their corneas (13.2% or $n = 9$), the disapproval of their family (10.3% or $n = 7$), religious restrictions (4.4% or $n = 3$), lack of information (2.9% or $n = 2$) and other personal reasons (20.6% or $n = 14$).

Finally, for the 724 (40.9%) participants who replied at the end of the survey that they would seriously consider

becoming a cornea donor if they had more information, the main motives were the opportunity to give the gift of sight to a fellow citizen (62.6% or $n = 453$) and the nobility of the act of donation (31.4% or $n = 227$). These motives are similar to the ones listed by the 977 participants who were positive towards cornea donation at the end of the survey. In contrast, though, to the 68 participants whose major barrier towards cornea donation was the belief that the body must remain intact after death, the major deterrents for the aforementioned 724 participants were lack of information (40.1% or $n = 290$) and concerns about the use of their corneas (20.0% or $n = 145$).

DISCUSSION

This is the first study using an interactive online survey in order to assess willingness to become a cornea donor at baseline and after a 5 min educational questionnaire. Willingness to donate increased from 40.6% to 55.2% in a statistically significant fashion across sexes, age groups and professions ([table 3](#)). This result is comparable to the one from the last Eurobarometer survey in 2015, where 48% (487/1015) of Greek participants answered that they are willing to donate parts of their eye such as the cornea.¹¹ In addition, only 3.8% of respondents would not become a cornea donor whatsoever at the end of the survey, while the rest 40.9% would seriously consider becoming a cornea donor if additional information was provided. Evaluating the willingness of a population to participate in organ donation is necessary for any new endeavour towards that prospect—be it cornea donation or soft tissue donation (eg, skin, tendons)—and is particularly relevant for any country that relies on imported tissue and wishes to establish its own donation programme. Given the lack of cadaveric donation in Greece and the demand for corneal transplants that exceed local tissue supply from brain-dead multiorgan donors by at least 20-fold, we regard this survey as a necessary step in order to assess the feasibility of establishing a programme of cadaveric tissue donation in Greece.

Participants who were aware about cornea donation and transplantation were more positive to becoming future donors at the beginning of the survey (61.9%) compared with those who had no such knowledge (25%–32.2%,

table 4), a finding that is similar to the results of an analogous survey in Singapore.⁹ Moreover, those who were less aware of these issues showed the greatest percentile increase (82.1%–84.1% compared with 10.7% of the more informed ones) in willingness to donate by the end of the survey. A similar trend was obvious in the percentile increase of willingness to donate between those whose studies or work were unrelated to the medical field and those whose studies or work were related to the medical field (eg, doctors, nurses, medical students). The former group showed significantly greater increase in willingness to become a cornea donor by the end of the survey (44.8% increase) compared with the latter one (23.1%, see table 3). Both of the above observations underscore the importance of targeting the part of the population that is less likely to be aware of the donation process in future campaigns. The finding that increased knowledge is associated with increased willingness to donate is similar to the results of analogous surveys in Singapore, Ethiopia and China.^{9 12–16} Lack of awareness about eye donation and lack of knowledge about corneal transplantation are cited as the only modifiable factors that may change the attitudes of certain communities towards donation.⁴

Our survey highlights the fact that the vast majority of participants (85.6%) was unaware of the Greek legislature concerning organ donations and the decisive role of the family in the donation process. Greece, along with other European countries such as Italy, Norway, Croatia and Bulgaria, has adopted a ‘soft’ opt-out system (table 5).^{10 17–20}

More precisely, anyone is regarded a potential donor, apart from those who have officially declared the opposite. However, if the family of the deceased disagrees, donation is not completed. Therefore, even though opt-out systems are generally associated with a higher procurement rate than opt-in systems (ie, where informed consent is required to be a donor), Greece has not had similar results. The fact that the vast majority of the Greek population was not familiar with this particularity in Greek legislation is yet another obstacle to overcome.

The low donation rates in Greece should not be attributed only to the decisive role of the family and the legislative ambiguity. In fact, countries with opt-out systems similar to Greece like Croatia, Italy and Norway have much higher rates, almost equal to those of ‘hard’ (ie, where approval of the family is not regularly required) opt-out countries like Austria, Belgium and Spain (table 5).^{10 17–20} Moreover, countries with opt-in systems like USA or the UK have among the highest procurement rates for organ donation (table 5).^{10 17–20}

Similar trends are also found in cornea donation rates where USA, an opt-in country, is by far the first country in cornea donation followed by Italy, a soft opt-out country similar to Greece.³ In our survey 40.9% of the participants claimed that they would seriously consider becoming a cornea donor if they had more information about the process and only 3.8% were negative to donation whatsoever. Though the idiosyncrasies of different western nations may partly account for the differences in donation rates, our results indicate that campaigns disseminating the value of organ and tissue donation can play a major role in increasing donation rates independent of the donation system.

In our survey the opportunity to give the gift of sight to a fellow citizen and the nobility of the act of donation were listed as the main motives in favour of donation, while body disfigurement after death was listed as the major deterrent. Similar reasons were cited in questionnaires carried out in India^{6–8} and Ethiopia^{14 15} in spite of the significant religious and cultural differences between Greece and the aforementioned countries. Finally, in a Toronto survey the main motive to become a donor was personal experience with cornea donation and transplantation and good results from the operation, while religion was listed as the major deterrent.⁵

The current study is the first attempting to assess the knowledge and beliefs of the Greek population towards cornea donation and the first to show that even a 5 min interactive online survey can have a significant impact on changing the mentality towards organ donation. We live

Table 5 Consent to donation systems in Australia, USA and European countries and organ procurement rates*

Opt-in consent	Organs procured/ million 2016	Opt-out consent	Organs procured/ million 2016	Opt-out + family consent	Organs procured/ million 2016
USA	30.76	Spain	43.8	Croatia	39.52
The UK	21.52	Belgium	30.79	France†	28.73
Australia	20.70	The Czech Republic	25.33	Italy	24.72
Denmark	17.54	Austria	25.23	Norway	20.94
The Netherlands‡	14.71	Sweden	19.7	Bulgaria	5.49
Germany	10.62			Greece	4.68

*Data of the WHO-ONT (World Health Organization- Spanish Transplant Organization) Global Observatory on Donation and Transplantation (accessed 2 February 2019).

†An opt-out system began in France in 2017. Up until December 2016, France also had an ‘opt-out + family consent’ system.

‡The Netherlands legislature changed to an opt-out system in 2018.

in an online era, so the use of social media or applications can play a major role in educating the public about the benefits of cornea donation as well as the logistic details of the process in order to increase donation rates, especially in countries that are not self-sufficient.

Contributors DT, AT, DK, DM, EK and SP thought about the concept of the online questionnaire, participated in its design and its distribution. DT was responsible for the statistics, which were reviewed by AT and SP. Interpretation of data was made by AT, DT and SP. The manuscript was written by DT and AT and was substantively revised by SP. All authors reviewed the final manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon request.

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