

# Development of an information brochure on corneal transplantation and increasing the willingness to donate corneas

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**Ανάπτυξη ενημερωτικού φυλλαδίου για τη μεταμόσχευση κερατοειδούς και την αύξηση της προθυμίας δωρεάς του**

*Abstract at the end of the article*

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**Introduction:** Corneal diseases such as bullous keratopathy, keratoconus, descemetocoele, eye infections that do not respond to antimicrobial therapy, and penetrating eye injuries can lead to blindness. When visual function has been irreversibly damaged and any conservative, surgical or other medical treatment has failed, corneal transplantation is the only treatment option. However, there is a worldwide shortage of corneal transplants.

**Aim:** The aim of the present study was the development of a cornea transplantation information/educational brochure capable to raise cornea donation-related willingness of the public.

**Materials and Methods:** A mixed methods study for the development of an information/educational brochure in raising public's willingness towards cornea donation was carried out in December 2021. The study participants were 25 ophthalmology residents and specialists, as well as nurses. For the data collection, an interview guide was used. For the quantitative data descriptive analysis, the IBM SPSS 28 software package was used, and for the coding and further analysis of the qualitative ones, the software program NVivo (Released 1.0).

**Results:** Regarding the socio-demographic characteristics of physicians and nurses, 14/25 (56%) were female, 18/25 (72%) were aged 26-35 years, 22/25 (88%) were physicians, 17/25 (68%) held a bachelor or a professional (MD) degree, and 13/25 (52%) responded that they could use the brochure in their practice. From the analysis of the qualitative question to the 25 experts, "What improvements could be made to make the brochure more effective?", the following four themes emerged: (i) "No comments on possible improvements", 15/25 (60%); (ii) "Very positive statements regarding the brochure", 6/25

(24%); (iii) "Suggestions for changes to the images/illustrations" 2/25 (8%); and (iv) "Suggestions for changes to the brochure's text order" 3/25 (12%).

**Conclusion:** The brochure produced to increase the public's willingness towards cornea donation from this study was considered adequate and able to achieve its purpose. To confirm the above hypothesis, future longitudinal/experimental studies should be conducted.

**Keywords:** Corneal transplantation; cornea donation; information/educational brochure; public.

## Introduction

The cornea is the transparent structure that acts as the main infectious and supportive barrier, as well as the proper front refractive exterior, of the eye.<sup>1,2</sup> Diseases of the cornea, such as bullous keratopathy, keratoconus, descemetocoele, eye infections unresponsive to antimicrobial therapy and perforating eye injuries,<sup>2,3</sup> can lead to blindness.<sup>4,5</sup> According to the literature,<sup>4,5</sup> corneal blindness accounted for 4.0% of the global visual impairment in 2010. When corneal transparency has been compromised and any conservative, surgical or other medical treatment has failed, corneal transplantation is the only therapeutic option.<sup>2,3,6,7</sup> Cornea transplants comprise the most common type of human tissue graft used globally with more than 180,000 corneal grafts being transplanted annually. It involves the replacement of the unhealthy host corneal tissue by disease free, clear, donor tissue.<sup>2,3,6,7</sup> However, it has been estimated that only 1 out of 70 patients eligible for a corneal graft will, in fact, receive it due to the worldwide shortage of cornea donors.<sup>7</sup>

In order to tackle the shortage of available corneal transplants, interventional studies aiming to enhance the willingness towards corneal tissue donation have been conducted.<sup>8,9</sup> For example, Tsigkos et al.,<sup>9</sup> through a quasi-experiment with a within group research design, found that a five-minute online educational intervention regarding cornea-related diseases and transplantation had an immediate effect on raising donation awareness by 14.7%. Bae and Kang<sup>8</sup> also evaluated an entertainment-educational show to shift social norms about organ or tissue donation for people with poor visual function. In that study,<sup>8</sup> the number of signed corneal donor cards increased from 1239 to 13733 in four months. According to the literature,<sup>10</sup> the brochure as a health education tool is acceptable to the intended au-

dience. However, no study to date has evaluated the effect of an information/educational brochure on increasing the public's willingness to become a cornea donor.

## Aim

The aim of the present study was the development of a cornea transplantation informational/educational brochure in order to raise cornea donation-related willingness of the public as a first step for a related subsequent intervention study.

## Research questions

1. What are the socio-demographic characteristics (gender, age -years-, type of employee, education level) of the evaluators of the brochure?
2. What are the themes, the broad categories represented by the data, from the qualitative analysis of the data on the suitability/effectiveness of the brochure?

## Materials and Methods

### Study design

A mixed methods (quantitative and qualitative) study for the development of an informational/educational brochure in raising willingness towards cornea donation was carried out.

### Setting

The study was conducted in the outpatient ophthalmology clinics of a large hospital in Athens, Greece. Since the process of obtaining information to create the brochure was anonymous, no General Data Protection Regulation (GDPR) compliance or ethics committee approval was required.<sup>11</sup>

### Research subjects

The participants of the study were ophthalmology residents and specialists, as well as nurses.

### Recruitment

Twenty-five ophthalmology residents and specialists, as well as nurses were approached by the research team in the hospital's outpatient ophthalmology clinics in December 2021.

### Data collection

An interview guide was used for data collection which included:

- Close-ended questions on socio-demographic data
- A five-point Likert-type question regarding the likelihood of using the informative/educational brochure to increase one's willingness, among the public, to donate corneas
- An open-ended question regarding improvements that could be made to make the brochure more effective.

### Measurements

The parameters that were measured were:

- *Socio-demographic characteristics:* Gender, age (years), type of employee, education level,
- *Perception of the likelihood of using the brochure,* and
- *Suggestions for improving the brochure to make it more effective.*

### Instrumentation – procedures

#### *Step 1: Set up an expert group.*

Initially, an expert group was set up to design the informational/educational brochure. An evidence-based method for evaluating a scientific tool, such as a questionnaire or a health education brochure, is an expert group. To ensure the effectiveness of the expert group, its members should come from different disciplines relevant to the issue under investigation.<sup>12</sup> In addition, according to Creswell, a good number of members for an expert group is four people.<sup>13</sup> The members of the expert panel for this study were an assistant professor of ophthalmology with a relevant publication record, a doctor in nursing with formal knowledge of 2D computer-aided design and two physicians specializing in ophthalmology who were interested in the project.

#### *Step 2: Design of a draft informational/educational bro-*

*chure on corneal transplantation and corneal donation.*

An informational/educational brochure on corneal transplantation and donation was designed by four health scientists, one assistant professor of ophthalmology, one doctor in nursing and two ophthalmology residents, roughly (modifications were made as necessary) based on the guidelines by Lampert et al.<sup>14</sup> A standardized strategy with four steps for developing and validating written information for patients was used as follows:

- Step 1: Initial requirements analysis that identifies the needs and constraints of the target population
- Step 2: Readability assessment
- Step 3: Assessment of the appropriateness of the informational/educational material<sup>15</sup>
- Step 4: Testing on the target population.

The modifications/adaptations with respect to the Lampert et al.<sup>14</sup> guidelines were the omission of the readability assessment step (in steps 2 and 3) due to the nature of the educational intervention with a brochure, which is more appropriate for an educated population (in a population with low education or without any educational background a more appropriate health education tool would be e.g. a talk). In particular, the quality of the brochure was assessed using a mixed-methods approach, using a modified version of the "Purchase Intent Scale" and a qualitative question on any suggested improvements by respondents.<sup>16,17</sup> Considering that, in line with Doak et al.,<sup>15</sup> an educational brochure could be a product of a company at a financial cost, a modified "Purchase Intent Scale"<sup>16,17</sup> could be considered a suitable tool for evaluating the validity of such informative/educational material. It should also be noted that questionnaires/scales related to purchase intention have been positively correlated with expected behavior in the literature,<sup>17</sup> making their results good predictors of expected behavior. The modified items of the "Purchase Intent Scale", in the context of the question "Which of the following statements best describes your ability to use this informational/educational brochure to increase someone's willingness to become a corneal donor?", structured on a five-point Likert-type scale, were as follows:<sup>16</sup>

- I would definitely use it
- I would probably use it
- I am not sure I would use it
- Most likely I would not use it, and

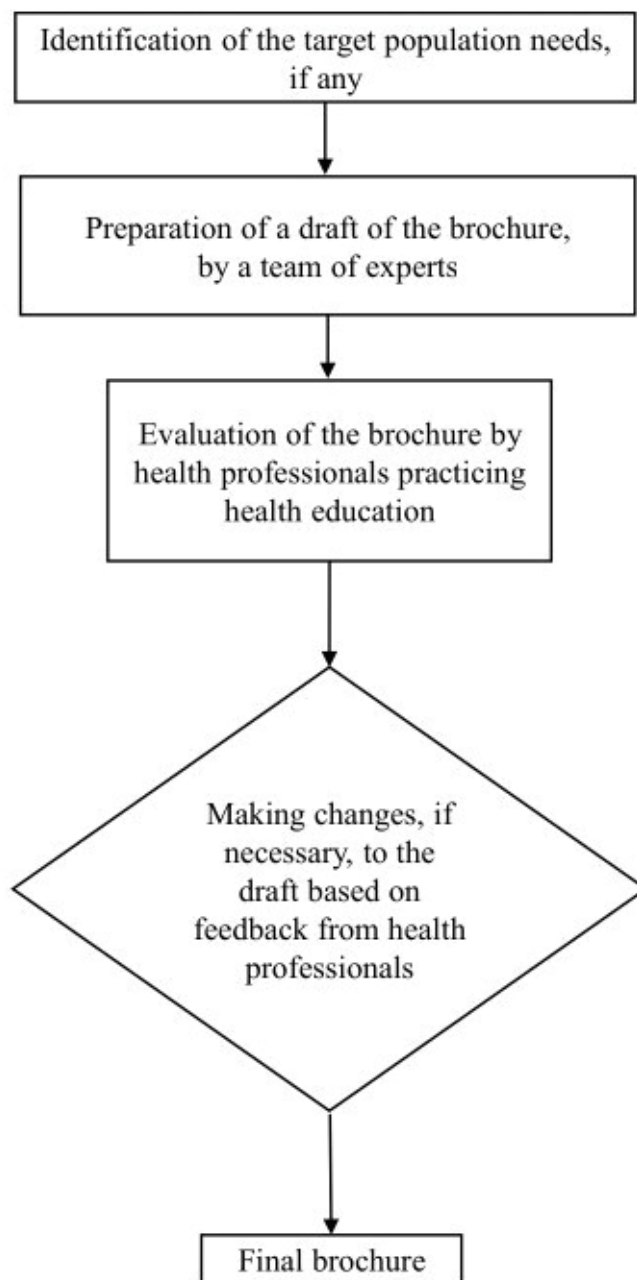


Figure 1. Brochure development process.

- Definitely I would not use it.

The reason for applying the modified "Purchase Intent Scale" to physicians and nurses is that these health professionals are considered experts in the field of health education and therefore their responses are valid. The physical/imaging characteristics of the questionnaire

included the following:

- An A4 paper, printed double-sided and folded three times (horizontally)
- A text with information about corneal transplantation, written in Greek, and
- Pictures and illustrations.

**Table 1.** Frequencies of the brochure assessment responders' characteristics

Sociodemographic Characteristics	n	Results*
Gender	(25)	Women=56.0%; Men=44.0%
Age group (years)	(25)	26-35=72.0%; 36-45=16.0%; 46-60=12.0%
Personnel type	(25)	Physician=88.0%; Nurse=12.0%
Education level	(25)	BSc degree=12.0%; Master's degree=24.0%; Professional (MD) degree=56.0%; PhD=8.0%

\*Results are %

**Table 2.** Likelihood of brochure usage by the respondents

Characteristics	N	Results*
<b>Probability</b>		
Probability of brochure usage	(25)	«I would probably use it»=52.0%; «I would definitely use it»=48.0%
Overall likelihood of using the brochure (1-5)	(25)	4.48±0.51

\*Results are %, and Mean ± Standard deviation

Permission to use the images and illustrations included in the brochure was requested where possible.

Regarding the electronic creation of the brochure, Microsoft Office 365 software was used. The flowchart of the process of designing the brochure to increase willingness towards cornea donation is shown in Figure 1.<sup>14</sup>

The main text of the brochure was based on the content of a relevant website of the Hellenic National Transplant Organization (EOM),<sup>18</sup> the study by Amiri et al.<sup>19</sup> and established ophthalmology literature sources.<sup>2</sup>

*Step 3: Evaluate the validity of the brochure by distributing the modified "Purchase Intent Scale" to a sample of physicians and nurses.*

- To assess the validity of the brochure, in terms of its content and its appropriateness, a questionnaire was distributed to a sample of 25 physicians and nurses in the outpatient ophthalmology clinics of a general and university hospital in Athens, Greece. This questionnaire consisted of two sections, a five-point Likert-type question ("I would definitely use it", "I would probably use it", "I am not sure I would use it", "Most likely I would not use it", and "Definitely I would not use it") and an

open-ended question about any suggested improvements/changes.

### Data - statistical analysis

Descriptive statistical analysis took place by using the IBM SPSS 28 software package.

In the context of the descriptive analysis, the frequencies of the sociodemographic, and probability characteristics of the physicians and nurses were calculated.

For the analysis of the present study qualitative data, the data were coded and further analyzed using the software program NVivo (Release 1.0).

### Results

#### Quantitative descriptive

Of the respondents, 14/25 (56.0%) were female, 18/25 (72.0%) were in the "26-35" age group, 22/25 (88.0%) were physicians, 17/25 (68.0%) had a BSc or professional degree (MD), 13/25 (52.0%) responded that they would probably use the brochure, and the mean score on a 1-5 Likert-type scale was 4.48±0.51, with "5" being the highest positive value.

**Table 3.** Suggested improvements to the brochure by the group of respondents.

Theme		Percentage of the responders*
No comments on possible improvements		15/25 (60%)
Very positive statements regarding the brochure	«The brochure is adequate»	6/25 (24%)
	«Nothing further»	
	«In my opinion it does not need any improvement because it is absolutely satisfactory»	
	«The brochure is very informative»	
	«Excellent»	
Suggestions for changes on figures/images	«Change of the cover photo»	2/25 (8%)
	«Change the image on the first page»	
Suggestions for changes on the brochure's main text	«Change the term corneal blindness with the term e.g., corneal insufficiency»	3/25 (12%)
	«Add transplant techniques (PK, DALK, DSAEK, DMEK)»	
	«The '1 donor can benefit 4 people', to go ahead»	
	«Sources at the end»	

\*Results are percentage of the total, and (%)

The quantitative descriptive results are presented in Tables 1 and 2.

### ***Inferential***

From the qualitative data analysis, four themes emerged: 15/25 (60%), "no comments on possible improvements", 6/25 (24%), "very positive statements regarding the brochure", 2/25 (8%), "suggestions for changes to the images/illustrations", and 3/25 (12%), "suggestions for changes to the brochure's main text" (Table 3). The brochure produced, in English language, is presented in Appendix I.

### **Discussion**

A worldwide shortage of corneal grafts prevents a significant number of patients to have their vision restored on a global level. It is estimated that there is one available graft for every 70 visually impaired patients who could benefit from a corneal transplant.<sup>7</sup>

In this study 56.0% of the participants were female and the self-perceived probability of using the produced brochure to increase the public's willingness to donate

corneas was  $4.48 \pm 0.51$  on a 1-5 Likert-type scale. Regarding the qualitative results, 24% of the respondents responded with statements related to adequacy of the brochure. According to the literature,<sup>10</sup> the brochure as a health education tool is acceptable to the intended audience. In the current study, a team of four health scientists (a professor of ophthalmology, a Doctor of Nursing and two ophthalmology residents) designed an informational/educational brochure on cornea and organ donation, to be used to raise awareness of the public's willingness to become a cornea donor.

Consistent with both the quantitative and qualitative results of this study, the brochure produced to increase the public's willingness towards cornea donation could be considered adequate and able to achieve its purpose. Du Plessis et al.,<sup>20</sup> examined the use of continuous pulse oximetric monitoring of newborns as a non-invasive and non-intrusive standard of care to promote early and safe skin-to-skin contact between mothers and newborns immediately after birth and gathered feedback of acceptability from obstetric staff and mothers. They also administered an educational brochure that improved mothers' knowledge of the risks and benefits of contin-

uous pulse oximetric monitoring ( $p=0.01$ ). In addition, Noh et al.,<sup>21</sup> as part of an examination of the effectiveness of an educational intervention in improving palliative care knowledge among informal caregivers of older adults with cognitive impairment, administered an informational brochure that improved the level of palliative care knowledge among informal caregivers of chronically or severely ill older adults with cognitive impairment ( $p<0.001$ ), particularly among Black caregivers ( $p<0.05$ ).<sup>21</sup> Another study on the effectiveness of an educational brochure is the one by Sagir and Altinel,<sup>22</sup> who examined the effect of an educational brochure on testicular cancer

and its early diagnosis on participants' health beliefs and self-examination. After administration of the brochure, a significant difference was found between the scores of the experimental group and the control group in terms of severity/care, health benefit and motivation, barriers, and self-efficacy ( $p < 0.05$ ). Also, the self-examination rate was determined as 83.3% in the experimental group and 4.5% in the control group.

To confirm the hypothesis that the present study brochure can increase the public's willingness to donate corneas, relevant longitudinal/experimental studies using it need to be conducted.

## Appendix I. The corneal transplantation information/educational brochure in raising public's willingness towards cornea donation.

### What is the cornea?

It is the transparent, shiny layer of the front part of the eye that allows light to enter the inside of the eye (like a "glass"), which allows us to see.

Sometimes the cornea becomes cloudy. There are many reasons, such as injuries or infections. A likely outcome? Not seeing well anymore or going blind completely.



In the year 2010 about 1.5 million people lost their vision due to damage to their cornea.

When these advanced conditions cannot be treated with medications or other surgical interventions, the only solution to improve vision is a *corneal transplant*.

### Who is considered a corneal donor?



A corneal donor is any person who during their lifetime has expressed a wish to donate their corneas after they die.

The donor's corneas are removed only if the donor's family agrees.

### What is corneal transplantation?

Corneal transplantation is a surgical procedure that requires the following steps:

- Up to 24 hours after the donor's death, if the donor's family agrees, the corneas are harvested, i.e., the donor's corneas are surgically removed, and
- If the corneas are healthy, they are surgically placed in patients within about 10 days of being procured (corneal transplantation).

### What is corneal transplantation?

Keep in mind that this tissue does not have veins and arteries, as other organs in our body, such as the heart and liver do. This has the following important advantage:

The risk of the patient's body not accepting the cornea and rejecting it, i.e. clouding of the graft, is small.

Corneal graft rejection is prevented by instilling corticosteroid drops, without giving pills that cause immunosuppression (i.e. reducing the body's defenses), as for example is done after a kidney transplant.

In recent years, new surgical techniques have been developed, which have very low graft rejection rates compared to earlier ones. They also help to improve vision in a very short time and require little or no stitches.

With a corneal transplant, a person with corneal blindness is (very) likely to regain their vision, which will significantly improve their daily life, for example:

- Driving
- Reading and seeing colors, and
- Reducing dependence on others

**1 donor who gives his 2 corneas can benefit  
4 patients**

**It has been estimated that for every 70 patients  
who need a corneal transplant, there is only  
one graft available**

**Πηγή:**

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\* From: <https://www.rchsd.org/health/articles/corneal-abrasions-3/>. (Accessed: 26.6.2021)

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† Illustrations showing corneal optical change with Fuchs endothelial corneal dystrophy (FECD) progression. Available at: [https://ars.els-cdn.com/content/image/1-s2.0-S0002939420305547-gr6\\_fig.jpg](https://ars.els-cdn.com/content/image/1-s2.0-S0002939420305547-gr6_fig.jpg) (Accessed: 7.1.2022)

†† Available at: <https://lakeanstoneye.com/procedures/corneal-transplantation/>. (Accessed: 26.6.2021)

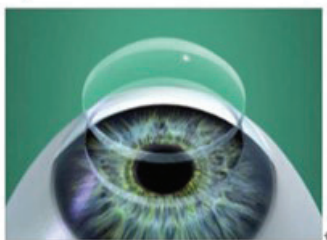
**Become a corneal  
donor!**

**Information to the competent authority:**

**National Transplantation Organisation**

**Anastasiou Tsocha 5, Athens 115 21**

**Telephone: 21 3202 7000**



**Brochure editing:**

**University of Athens Medical School First  
Ophthalmology Clinic / Cornea Department**

**Corneal  
Transplantation**





**Ανάπτυξη ενημερωτικού φυλλαδίου για τη μεταμόσχευση κερατοειδούς και την αύξηση της προθυμίας δωρεάς του**

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**Εισαγωγή:** Οι παθήσεις του κερατοειδούς, όπως η βολβοειδής κερατοπάθεια, ο κερατόκωνος, η δεσμετοκίλη, οι οφθαλμικές λοιμώξεις που δεν ανταποκρίνονται στην αντιμικροβιακή θεραπεία και οι διατιτραίνοντες τραυματισμοί των ματιών μπορούν να οδηγήσουν σε τύφλωση. Όταν η οπτική λειτουργία έχει υποστεί μη αναστρέψιμη βλάβη και κάθε συντηρητική, χειρουργική ή άλλη ιατρική θεραπεία έχει αποτύχει, η μεταμόσχευση κερατοειδούς αποτελεί τη μόνη θεραπευτική επιλογή. Ωστόσο, υπάρχει παγκόσμια έλλειψη μοσχευμάτων κερατοειδούς.

**Σκοπός:** Σκοπός της παρούσας μελέτης ήταν η ανάπτυξη ενός ενημερωτικού/εκπαιδευτικού φυλλαδίου για τη μεταμόσχευση κερατοειδούς με στόχο την αύξηση της προθυμίας του κοινού σχετικά με τη δωρεά κερατοειδούς.

**Υλικό και μέθοδος:** Τον Δεκέμβριο του 2021 διεξήχθη μια μελέτη μεικτών μεθόδων για την ανάπτυξη ενός ενημερωτικού/εκπαιδευτικού φυλλαδίου για την αύξηση της προθυμίας του κοινού προς τη δωρεά κερατοειδούς. Οι συμμετέχοντες στη μελέτη ήταν 25 ειδικευμένοι και ειδικοί οφθαλμίατροι, καθώς και νοσηλευτές. Για τη συλλογή δεδομένων χρησιμοποιήθηκε οδηγός συνέντευξης. Για την περιγραφική ανάλυση των ποσοτικών δεδομένων χρησιμοποιήθηκε το λογισμικό πακέτο IBM SPSS 28 και για την κωδικοποίηση και περαιτέρω ανάλυση των ποιοτικών το λογισμικό πρόγραμμα NVivo (Released 1.0).

**Αποτελέσματα:** Όσον αφορά τα κοινωνικο-δημογραφικά χαρακτηριστικά των ιατρών και των νοσηλευτών, 14/25 (56%) ήταν γυναίκες, 18/25 (72%) ήταν ηλικίας 26-35 ετών, 22/25 (88%) ήταν ιατροί, 17/25 (68%) κατείχαν πτυχίο ή επαγγελματικό πτυχίο (MD) και 13/25 (52%) απάντησαν ότι θα μπορούσαν να χρησιμοποιήσουν το φυλλάδιο στην πρακτική τους. Από την ανάλυση της ποιοτικής ερώτησης προς τους 25 εμπειρογνώμονες, «Ποιες βελτιώσεις θα μπορούσαν να γίνουν για να γίνει το φυλλάδιο πιο αποτελεσματικό;», προέκυψαν τα ακόλουθα τέσσερα θέματα: (i) «Κανένα σχόλιο για πιθανές βελτιώσεις», 15/25 (60%), (ii) «Πολύ θετικές δηλώσεις σχετικά με το φυλλάδιο», 6/25 (24%), (iii) «Προτάσεις για αλλαγές στις εικόνες/εικονογραφήσεις» 2/25 (8%) και (iv) «Προτάσεις για αλλαγές στη σειρά του κειμένου του φυλλαδίου» 3/25 (12%). **Συμπεράσματα:** Το φυλλάδιο που παρήχθη για την αύξηση της προθυμίας του κοινού προς τη δωρεά κερατοειδούς από την παρούσα μελέτη θεωρήθηκε επαρκές και ικανό να επιτύχει τον σκοπό του. Για να επιβεβαιωθεί η παραπάνω υπόθεση, θα πρέπει να διεξαχθούν μελλοντικές διαχρονικές/πειραματικές μελέτες.

**Λέξεις-κλειδιά:** Μεταμόσχευση κερατοειδούς, δωρεά κερατοειδούς, ενημερωτικό/εκπαιδευτικό φυλλάδιο, κοινό.

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