Accessibility to and Quality of Human Eye Tissue for Research: A Cross-Sectional Survey of ARVO Members

W. Daniel Stamer,1 Andrew M. Williams,2 Stephen Pflugfelder,3 and Sarah E. Coupland4

1Department of Ophthalmology, Duke University Medical Center, Durham, North Carolina, United States
2Department of Ophthalmology, University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania, United States
3Department of Ophthalmology, Baylor University College of Medicine, Houston, Texas, United States
4Molecular and Clinical Cancer Medicine, University of Liverpool, Liverpool, United Kingdom

Correspondence: W. Daniel Stamer, Duke University Eye Center, AERI Room 4008, 2351 Erwin Road, Durham, NC 27705, USA; dan.stamer@duke.edu.
Submitted: January 11, 2018
Accepted: June 12, 2018
Citation: Stamer WD, Williams AM, Pflugfelder S, Coupland SE. Accessibility to and quality of human eye tissue for research: a cross-sectional survey of ARVO members. Invest Ophthalmol Vis Sci. 2018;59:4783–4792. https://doi.org/10.1167/iovs.18-25319

Purpose. To assess experiences of vision scientists concerning the availability, quality, and documentation of human eye tissue for research, and to elicit researcher feedback about the establishment of an online portal that pairs eye bank capabilities with researcher needs.

Methods. An online survey was designed by a working group of vision scientists and eye bank personnel and sent to members of ARVO.

Results. A total of 407 responses were received from across ARVO scientific sections and career stages. Most respondents report typically obtaining human eye tissue from their local eye bank (57%). Almost half (45%) find it “difficult” or “very difficult” to get an adequate quantity of human eye tissue for their research, and 88% report that they would use more human eye tissue if it were more accessible. Regarding tissue quality, 43% of respondents regularly limit the scope of their work due to difficulty obtaining tissue that meets their needs, and almost half (43%) indicate that they question their findings due to tissue quality at least sometimes. Respondents uniformly desire more documentation about ocular tissue than they typically receive. Most (62%) would “definitely” or “very likely” use a proposed online resource to facilitate connections between eye banks and researchers.

Conclusions. Vision scientists report difficulty in obtaining human eye tissue with the quality and clinical documentation required for their research. An online portal may better help pair researcher needs and eye bank capabilities.

Keywords: DHX38, early-onset retinitis pigmentosa, exome sequencing, linkage analysis, retinal dystrophy

The availability of quality human eye tissue is indispensable for advancing research on blinding diseases. Although animal models and ocular tissues are a useful resource, the most prevalent human eye diseases, such as primary open-angle glaucoma and AMD, uniquely occur in humans and are difficult to model in animals because of anatomical differences, genetics, and other contributors to these complex diseases. Thus, human eye tissues and samples are needed to help understand the relationship among genetic disposition, environmental influences, and aging on the etiology of complex eye disease. In particular, human eye tissue that is of high quality (i.e., short death-to-preservation intervals) and has relevant clinical documentation allows targeted experimentation to dissect out mechanisms that underlie pathology responsible for these complicated diseases.

Unfortunately, there has been a gradual decline in the availability of human eye tissues for research.1 Statistics from the Eye Bank Association of America (EBAA) demonstrate a persistent downward trend in the proportion of donated tissue that is distributed from eye banks for research use (Fig. 1).2–4 Additionally, the tissue quality and clinical documentation that researchers receive often do not align with that desired for experimentation, as eye bank procurement processes are primarily centered on the acquisition of donor tissue for clinical transplantation. Specifically, procurement protocols are not always well suited to serve researchers’ needs for quantity, freshness, donor characteristics, and preparation methods of ocular tissue. Due to these concerns, scientists have called for ways to improve the accessibility and quality of donor eyes for research, including innovative collaborations with eye banks.5

Partnerships between vision scientists and eye banks are critical to foster the shared mission of both groups to advance research of blinding eye diseases.6 Scientists have indicated that their local eye bank is their primary source of tissue, and close relationships between researchers and eye banks are required for fulfillment of particular tissue requests.1 However, the local nature of researcher–eye bank relationships may not always pair the eye bank capabilities with specific researcher tissue needs.

In pursuit of their shared mission of advancing vision research, ARVO and EBAA convened focus groups to discuss eye bank capabilities and eye research needs and to determine how ARVO and EBAA can better connect their two communities. The following goals were identified at meetings of the ARVO and EBAA collaborative group over the past year: (1) to connect eye researchers and eye banks to improve access and availability of quality eye tissue; (2) to improve training and education on the preparation and use of tissue; and (3) to increase eye recoveries for research purposes.
To pursue the objective of connecting eye researchers and eye banks and to improve accessibility of quality eye tissue for research, ARVO and EBAA proposed an online portal as a service to researchers, linking researchers and eye banks directly. This resource would include an online listing of eye banks with associated capabilities and contacts. To assess the feasibility of the proposed research tissue portal, surveys were administered to ARVO and EBAA memberships, accessing their needs and challenges regarding donor eye tissue for research, and to inquire about utility of the proposed online portal.

Here we report results from the ARVO member survey regarding experiences with the accessibility and quality of human eye tissue for research, and to assess whether a proposed online eye tissue portal may be beneficial for researchers.

METHODS

Sample and Survey Instrument

The survey targeted three groups of ARVO members: (1) regular members and members in training who indicated in their online profile that they work with human eye tissue (e-mail messaging: “Share your preferences and needs”), (2) regular members who indicated that they do not work with human eye tissue (e-mail messaging: “Please share with your colleagues who work with human eye tissue”), and (3) regular members who did not indicate either (e-mail messaging: “This registry will be an important tool, please help us develop it by filling out the survey or sharing with colleagues who do”).

The survey questionnaire was based on previous instruments used in the biobanking literature. The survey questions were then refined with input from various stakeholders who participated in the ARVO and EBAA collaborative effort, including 11 vision researchers across subspecialty disciplines and five eye bank representatives from across the United States. These focus groups convened to discuss topics such as the availability and perceived quality of eye tissue available, sources of eye tissue for research, and potential solutions for improving the accessibility and quality of human eye tissue for research purposes. These sessions also focused on desired characteristics of an online portal hosted by ARVO for EBAA-member eye banks to post their research capabilities and costs as a service for ARVO researchers.

The finalized survey was uploaded to an online platform for e-mail distribution (MagnetMail; Higher Logic, Arlington, VA, USA). The final survey contained 21 items under the following sections: tissue sources, accessibility, and barriers; likelihood that researcher eye tissue portal would improve one’s work; and demographic information (see the Appendix for the full questionnaire).

Data Collection

The online survey link was distributed by e-mail to potential respondents on September 18, 2017 with the subject of “Eye Bank Survey” and a short message about the critical value of the researcher’s input on experiences with obtaining donor tissue for research. The e-mail body also indicated that the survey would take approximately 5 minutes to complete. A reminder e-mail was sent on September 28, 2017, with a similar message urging participation in the survey. The survey platform was closed by October 23, 2017.

Recoding of “Other” Responses

Many questionnaire items allowed respondents to select “other” and list a free response. These “other” responses were reviewed by the authors and, when appropriate, coded back to an existing response category. New categories were created as determined to be appropriate.

Collapsed Variables

Due to small sample sizes, responses to “country lived” were collapsed into larger geographic regions to aid in summarizing the results.

Statistical Analysis

Descriptive statistics are presented with counts and percentages. Quantitative data are summarized as mean ± SD. For comparison of “ideal” versus “typical” death-to-preservation time, a two-tailed paired Student’s t-test was performed for respondents who provided a response to both questions.
RESULTS

Sample Characteristics

E-mail messages containing an embedded link to the survey were sent to 7881 ARVO members, of which 7814 messages were marked as delivered and 3020 were opened. In total, there were 407 completed surveys, including 378 from ARVO members and 29 from nonmembers.

Demographic characteristics of respondents are summarized in Table 1. All sections of ARVO membership were represented, with the greatest numbers coming from cornea (21%), glaucoma (17%), and retinal cell biology (16%). Respondents originated from 34 different countries. Most respondents were from North America (67%), 16% were from Europe, 7% from Asia, and the remainder from Oceania, South America, or the Middle East. Of those who responded to the question (189), the overwhelming majority reported working up to 10 years, 16% reporting 10 to 25 years, and 58 reporting more than 25 years (231 abstaining). The most common primary professional focus cited was basic research (65), followed by clinical research (15) (311 abstaining).

Accessibility of Human Eye Tissue for Research

Most survey respondents (87%) reported using human eye tissue in their research, and there was a strong interest in using more tissue if it were easier to obtain. Respondents estimated using a mean of 4.61 human eyes in their research per month (range, 0–140; n = 235) and 31.611 human eyes per year (range, 0–1680; n = 338). Of the 13% who do not use human eye tissue, 82% indicated that they would do so if it were more readily available (Fig. 2). Ninety-two percent of respondents indicated that it is “very important” to conduct research on human eye tissue when rating importance on a seven-point scale.

When asked to identify a single source, most researchers reported typically obtaining human eye tissue from their local eye bank (57%); other common sources included the National Disease Research Interchange (NDRI, 8%) and other sources out of state (10%) or out of the country (8%) (Fig. 3). Free-texted “other” responses included research collaborators (2%), commercial supplier (1%), donors from a university hospital (1%), a university tissue bank (1%), and the former Foundation Fighting Blindness eye donor program (1%). In a separate question, 45% reported using surgical discard material in their research.

TABLE 1. Characteristics of the 407 Survey Respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Career stage</td>
<td></td>
</tr>
<tr>
<td>Student/Predoctor</td>
<td>15 (4)</td>
</tr>
<tr>
<td>Postgrad/Resident</td>
<td>10 (2)</td>
</tr>
<tr>
<td>Early career (up to 10 years)</td>
<td>30 (7)</td>
</tr>
<tr>
<td>Mid-career (10–25 years)</td>
<td>60 (15)</td>
</tr>
<tr>
<td>Late career (25+ years)</td>
<td>58 (14)</td>
</tr>
<tr>
<td>Post-career</td>
<td>3 (1)</td>
</tr>
<tr>
<td>Anonymous or blank response</td>
<td>231 (57)</td>
</tr>
<tr>
<td>Geographic region</td>
<td></td>
</tr>
<tr>
<td>North America</td>
<td>272 (67)</td>
</tr>
<tr>
<td>Europe</td>
<td>67 (16)</td>
</tr>
<tr>
<td>Asia</td>
<td>29 (7)</td>
</tr>
<tr>
<td>Oceania</td>
<td>14 (3)</td>
</tr>
<tr>
<td>South America</td>
<td>11 (3)</td>
</tr>
<tr>
<td>Middle East</td>
<td>3 (1)</td>
</tr>
<tr>
<td>Anonymous or blank response</td>
<td>11 (3)</td>
</tr>
<tr>
<td>ARVO section affiliation</td>
<td></td>
</tr>
<tr>
<td>Cornea</td>
<td>84 (21)</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>71 (17)</td>
</tr>
<tr>
<td>Retina Cell Biology</td>
<td>64 (16)</td>
</tr>
<tr>
<td>Retina</td>
<td>42 (10)</td>
</tr>
<tr>
<td>Biochemistry/Molecular Biology</td>
<td>28 (7)</td>
</tr>
<tr>
<td>Physiology/Pharmacology</td>
<td>23 (6)</td>
</tr>
<tr>
<td>Immunology/Microbiology</td>
<td>22 (5)</td>
</tr>
<tr>
<td>Lens</td>
<td>21 (5)</td>
</tr>
<tr>
<td>Anatomy and Pathology/Oncology</td>
<td>16 (4)</td>
</tr>
<tr>
<td>Clinical/Epidemiologic Research</td>
<td>9 (2)</td>
</tr>
<tr>
<td>Visual Neuroscience</td>
<td>9 (2)</td>
</tr>
<tr>
<td>Visual Psychophysics/Physiological Optics</td>
<td>4 (1)</td>
</tr>
<tr>
<td>Eye Movements/Strabismus/Ambylopia/Neuro-Ophthalmology</td>
<td>2 (0.5)</td>
</tr>
<tr>
<td>Anonymous or blank response</td>
<td>12 (3)</td>
</tr>
<tr>
<td>Primary professional focus</td>
<td></td>
</tr>
<tr>
<td>Basic research</td>
<td>65 (16)</td>
</tr>
<tr>
<td>Clinical research</td>
<td>15 (4)</td>
</tr>
<tr>
<td>Clinical practice</td>
<td>4 (1)</td>
</tr>
<tr>
<td>Surgical</td>
<td>3 (1)</td>
</tr>
<tr>
<td>Administrative</td>
<td>4 (1)</td>
</tr>
<tr>
<td>In-training basic research</td>
<td>2 (0.5)</td>
</tr>
<tr>
<td>Board of trustees</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td>Anonymous or blank response</td>
<td>315 (77)</td>
</tr>
</tbody>
</table>

FIGURE 2. Use of human eye tissue among respondents.
The typical cost of obtaining a whole globe for research, in U.S. dollars, averaged $481 (range, $0–$3000), among the 235 who responded to the question. The typical cost of a pair of globes was $845 (range, $0–$6000; n = 203).

Many researchers find it challenging to obtain the tissue they need. Almost half (43%) find it ‘‘difficult’’ or ‘‘very difficult’’ to obtain an adequate quantity of human eye tissue for their research, compared with 11% who find it ‘‘easy’’ or ‘‘very easy.’’ Of all respondents, 88% reported that they would use more human eye tissue in their research if it were more accessible (Fig. 4). Additionally, 43% of respondents indicated that they “often,” “usually,” or “always” limit the scope of their work due to difficulty obtaining human eye tissue that meets their needs (Fig. 5).

Quality and Documentation of Human Eye Tissue for Research

In addition to accessibility, donor eyes must meet the tissue quality and documentation standards required for experimental use. In particular, a short interval from patient death to tissue preservation correlates with higher tissue quality and freshness. There is a drastic mismatch between the “ideal” and the “typical” death-to-preservation time for researchers. Specifically, 60% of respondents indicated that their ideal death-to-preservation time is less than 6 hours, whereas only 18% typically receive tissue collected in this time frame (P < 0.001) (Fig. 6).

Concerns about tissue quality limit scientific inquiry. Almost half (43%) of respondents indicated that they question their findings or outcomes due to tissue quality at least sometimes, or in more than a quarter of experiments. Furthermore, 42% of researchers report an inability to use more than a quarter of human eye tissues acquired due to problems with the tissue itself (Table 2).

Although the information provided by the procurement agency generally aligns with the information that researchers consider ideal, scientists desire more documentation about the human eye tissue they receive. Specifically, the death-to-preservation time and tissue storage procedures are most commonly cited as important, and are typically provided with donor tissue. However, additional types of information are desired but not routinely available. In particular, medications and family history of donor had the largest percentage difference between information rated as ideal to have versus as typically provided, at +39% and +37%, respectively (Table 3).

Proposed Registry

Most researchers responded positively to a proposed online resource to facilitate connections between eye banks and researchers. Overall, 62% said they would “definitely” or “very likely” use such a resource (Fig. 7).

DISCUSSION

Due to difficulties in obtaining adequate human donor eye tissue for research, the collaboration between ARVO and EBAA set out to assess present challenges that researchers face regarding human eye tissue and the usefulness of an online tissue portal to connect vision researchers with eye banks. Our survey found that researchers struggle to acquire human eye tissue for research. Almost half report finding it difficult to acquire an adequate quantity of human eye tissue for their
work, and almost all respondents reported that they would use more human eye tissue if it were more accessible. There are also concerns about tissue quality and documentation. Alarmingly, researchers report that concerns about tissue quality sometimes lead them to question their results, and their scope of scientific experimentation is often limited due to condition of the tissue received. Respondents also report desiring much more clinical documentation with their donor tissue.

The caliber of scientific research is dependent on the quality of tissue specimens available, and there has been concern about the accessibility and quality of human eye tissue for research. Previously identified prohibitory factors in acquiring human eye tissue for research include lack of tissue meeting criteria, tissue cost, and absence of clinical documentation. The importance of high-quality specimens has grown even more recently with the development of sensitive assays that require fresh tissue, such as high-resolution “omic” analyses (genomic, proteomic, and metabolic). Unfortunately, only 18% of survey respondents received tissue with a death-to-preservation time of less than 6 hours to facilitate such analyses. Interestingly, almost half of respondents reported receiving human ocular research tissues from surgical discard.

Surgically resected eye samples (e.g., from enucleated tumor globes from consented patients), also allows for harvesting of nontumor material in the eye, assuming that it is not required for diagnostic purposes. There are very few established ocular oncology banks with all the required ethical approvals and financial resources to maintain them. The Liverpool Ocular Oncology Biobank (http://www.loorg.org/ocular-oncology-biobank-oob.html; provided in the public domain by Liverpool Ocular Oncology Research Group, Liverpool, UK) is one of the few, run by one of the authors (SEC), and comprises not only primary and metastatic uveal melanomas, but also normal ocular tissues from the enucleated globe not needed for diagnostics. This Biobank provided high-quality fresh uveal melanoma samples for The Cancer Genome Atlas uveal melanoma study, and is aiding the coordination of a virtual biobank across an EU consortium studying metastatic
uveal melanoma (https://www.umcure2020.org/en/; provided in the public domain by UMCure2020). Other ophthalmic biobanks concentrate on other intraocular tumors (e.g., retinoblastoma) (the guardians are Brenda Gallie and Helen Dimaras in Toronto, Canada), or inherited eye diseases (e.g., the DNA Bank at National Eye Institute, Bethesda, MD, USA).

Additional collaborative solutions have been proposed to address the challenges researchers face with acquiring human eye tissue. A proposed eye donation registry for research, in the form of an advanced directive was well received among a diverse population of ophthalmic patients, their family members, and eye care providers.8,9 In fact, a pledge-based donor program was successfully organized by the Foundation Fighting Blindness to collect specimens from patients with AMD or inherited retinal disease to send to a central site in Cleveland for research use. The program collected eye tissue from more than 1000 donors before it was closed in 2016.20 In another program, collaboration with the Miracles in Sight Eye Bank to facilitate processing of research tissue to Duke University laboratories yielded higher volume and increased freshness of tissue for research by changing the eye bank protocol for processing research-bound specimens.21 However, collaborative programs between eye banks and researchers are inherently local in nature, with associated limitations in scalability.

Data from our survey reflect the local nature of eye bank and researcher partnerships, with more than half of respondents reporting that their local eye bank is their primary source of research tissue, similar to described previously.1 However, the resulting silos of relationships between individual researchers and local eye banks may not consistently pair eye bank capabilities with researcher needs. As such, the tissue samples and patient populations available may limit research questions. These limitations call for larger-scale collaborations between tissue procurers and ophthalmic scientists.

There is a precedent for centralized programs to connect tissue with researchers on a national scale. One source is the NDRI, a clearinghouse provider of diverse human tissues that matches specimens received from organ procurement organizations with researcher protocols.22 In fact, 8% of researchers who responded to our survey report that the NDRI is their primary source of human eye tissue. However, the requirement of a minimized death-to-preservation time, specific ophthalmic tissue processing requests, and access to donor medical history can limit the utility of clearinghouse sources like NDRI for vision scientists. To expand the reach of their expertise in ophthalmic tissue processing, some larger eye banks already provide tissue for out-of-state researchers. For instance, the Lions Eye Institute for Transplant and Research in Tampa, Florida, was cited as the primary source of tissue for two researchers outside of Florida. Tissue requests between individual researchers and eye banks are handled by direct correspondence with the eye bank personnel.23 Notably, even interactions with distant eye banks require individual communication and needs assessment.
To facilitate the process of pairing researchers’ tissue requests with eye bank capabilities, the ARVO and EBAA Working Group has proposed a centralized online resource to match needs and services. The researcher eye tissue portal would allow each party to post the types of tissues they either seek or can provide, along with associated clinical documentation and tissue attributes. Most survey respondents indicated an interest in using such an online resource, with 62% indicating that they would ‘’definitely’’ or be ‘’very likely’’ to do so. The proposed research tissue portal would match eye bank services with particular researcher requests in tissue parameters and clinical documentation, which vision scientists require for their work. From the perspective of EBAA-member eye banks, a separate survey conducted by the EBAA found that most eye banks reported that they would use the proposed resource, citing lack of interaction with researchers as a common barrier for providing tissue for research (Corcoran KP, manuscript in preparation, 2018).

Data from the present survey of ARVO members, particularly regarding the types of information about tissue that researchers consider ideal to have, may help to guide development of the online portal. Areas of information desired could then be included with researchers’ tissue requests. Additionally, the growing implementation of electronic medical records in hospital and clinic settings can offer easier access to relevant clinical information, provided that such access is made explicit in the consent process. The establishment of a research tissue portal may also provide a platform to codify uniform eye bank practices for processing and documenting eye tissue for research, such as an “ARVO research tissue certification,” that could be developed in the future. Such a certification could allow for better standardization in reporting.

**Table 3. Ideal and Typical Information Known About Donor Tissue**

<table>
<thead>
<tr>
<th>Type of Information</th>
<th>Ideal to Know, n (%)</th>
<th>Typically Known, n (%)</th>
<th>% Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient medications</td>
<td>242 (59)</td>
<td>84 (21)</td>
<td>+39%</td>
</tr>
<tr>
<td>Patient family history</td>
<td>189 (46)</td>
<td>38 (9)</td>
<td>+37%</td>
</tr>
<tr>
<td>Tissue storage information</td>
<td>249 (61)</td>
<td>102 (25)</td>
<td>+36%</td>
</tr>
<tr>
<td>Use of standard operating procedures for collection</td>
<td>249 (61)</td>
<td>102 (25)</td>
<td>+36%</td>
</tr>
<tr>
<td>Quality control data on the tissue</td>
<td>249 (61)</td>
<td>102 (25)</td>
<td>+36%</td>
</tr>
<tr>
<td>Patient treatment outcomes</td>
<td>174 (43)</td>
<td>32 (8)</td>
<td>+35%</td>
</tr>
<tr>
<td>Smoking history</td>
<td>194 (48)</td>
<td>62 (15)</td>
<td>+32%</td>
</tr>
<tr>
<td>Pathological diagnosis</td>
<td>260 (64)</td>
<td>136 (33)</td>
<td>+30%</td>
</tr>
<tr>
<td>Patient past medical history</td>
<td>274 (67)</td>
<td>152 (37)</td>
<td>+30%</td>
</tr>
<tr>
<td>Clinical diagnosis</td>
<td>286 (70)</td>
<td>185 (45)</td>
<td>+25%</td>
</tr>
<tr>
<td>Patient complaint/history of present illness</td>
<td>226 (56)</td>
<td>141 (35)</td>
<td>+21%</td>
</tr>
<tr>
<td>Patient consent/authorization status</td>
<td>181 (44)</td>
<td>114 (28)</td>
<td>+16%</td>
</tr>
<tr>
<td>Cause of death</td>
<td>263 (65)</td>
<td>218 (54)</td>
<td>+11%</td>
</tr>
<tr>
<td>Patient demographics</td>
<td>257 (63)</td>
<td>216 (53)</td>
<td>+10%</td>
</tr>
<tr>
<td>Storage procedures</td>
<td>307 (75)</td>
<td>277 (68)</td>
<td>+7%</td>
</tr>
<tr>
<td>Death-to-preservation time</td>
<td>336 (83)</td>
<td>308 (76)</td>
<td>+7%</td>
</tr>
<tr>
<td>Does not apply or “other”</td>
<td>49 (12)</td>
<td>53 (13)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>407 (100)</td>
<td>407 (100)</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 7.** Researcher feedback on a proposed online resource to facilitate relationships between researchers and eye banks.
the conditions of tissue collection, transport, processing, and storage in publications, a practice that has been advocated for cancer biospecimens.\textsuperscript{21} Our survey has several limitations. Our response rate of 5% (13% of those who opened the e-mail solicitation), while consistent with prior large survey studies of scientists, may suggest that those who responded to the survey are not representative of the eye research community as a whole.\textsuperscript{2} Additionally, by the nature of survey studies, we rely on self-reported data, which may not always be accurate. Relatedly, we report on researcher interest in a hypothetical portal resource, which may not reflect the actual use of such a resource after potential users assess the details of the portal and how it could influence their work.

Another important limitation of any new large-scale resource is its associated costs. Further cost analysis would be required to assess the expense of designing and hosting the research tissue portal on the ARVO Web site, as well as associated maintenance and marketing expenses. Indirect costs, such as time investment required by eye banks and researchers to maintain posts or profiles, also would need to be considered. Additionally, shipping and storage expenses would need to be accounted for in researcher budgets. The mean costs reported for the tissue in this survey were $845 for bilateral eye tissue, with variability depending on the circumstances of individual eye banks. Notably, researchers have expressed willingness to pay more for higher-quality tissue and better documentation.\textsuperscript{1}

A final limitation of the proposed portal is that it would not in itself increase the number of individuals who choose to donate their eyes for research after death. However, greater collaborations with researchers could lead eye banks to more actively pursue consenting of donor families for research, particularly of registered donors whose tissue would not be eligible for clinical transplantation due to age of donor, conditions surrounding death, and/or especially presence of ocular disease.\textsuperscript{21} Additional efforts in educational campaigns about eye donation and formation of research registries also could help make connections with people who have an interest in donating their eyes but have not pledged to do so.\textsuperscript{25}

**CONCLUSIONS**

An overwhelming 92% of respondents indicated that it is “very important” to conduct research on human eye tissue; however, researchers express significant challenges in obtaining human eye tissue for their work, and they report a need for higher-quality samples with better clinical documentation than what they typically receive. Eye banks are well equipped to provide quality human eye tissue for scientists, and a collaborative online research tissue portal may help to pair researcher needs and eye bank capabilities more efficiently and on a larger scale than existing local partnerships.

**Acknowledgments**

The authors thank the members of the ARVO/EBAA collaborative group that includes Emily Chew, Justine Smith, Tim Olsen, Claude Burgoyne, Iris Rush, Joanne Olson, Kevin Corcoran, Corrina Patzer, Kathy Goode, Mark Greiner, and Alan Blake for helpful discussions. The authors also thank Jon Mallett for processing/analyzing survey results and construction of figures. Lastly, the authors thank Rand Allingham for his passionate advocacy in establishing a better system for connecting valuable human donor eye tissue with researchers.

**References**


**APPENDIX**

**ARVO Survey: Tell Us What You Think**

ARVO and the Eye Bank Association of America are working together to strengthen relationships between eye banks and eye researchers and to improve access to quality eye tissue. To that end, it will be helpful to learn more about researchers’ needs and challenges.

You are receiving this survey because your ARVO member profile indicates you use human eye tissue in your work.

The survey should take approximately 5 minutes to complete. We appreciate your participation.

1. **How important do you feel it is to do research on human eye tissue?**
   - Very important
   - Important
   - Somewhat important
   - Undecided
   - Somewhat unimportant
   - Unimportant
   - Very unimportant

2. **Where do you typically obtain human eye tissue for research?**
   - Local eye bank
   - National Disease Research Interchange (NDRI)
   - Out of state
   - Out of country
   - Other

3. **Are you using surgical discard from the operating room (OR)?**
   - Yes
   - No

4. **What is the typical cost of obtaining a whole globe for research?** (USD)
   - Single globe: $$
   - Pair: $$

5. **How many human eyes do you use in your research during the following time periods?**
   - Per month: ____
   - Per year: ____

6. **Would you use more human eye tissue in your research if it were more readily available?**
   - Yes
   - No

7. **What information do you typically know about the human eye tissue available to you in your work? (Select all that apply.)**
   - Death-to-preservation/enucleation time
   - Storage procedures
   - Patient demographics
   - Patient complaint/history of current illness
   - Patient past medical history
   - Patient family history
   - Clinical diagnosis
   - Pathological diagnosis
   - Patient treatment outcomes
   - Patient consent/authorization status
   - Quality control data on the tissue itself (e.g., use of standard operating procedures for collection, storage, and management)
   - Medications
   - Smoking history
   - Cause of death
   - Does not apply
   - Other

8. **If all barriers were removed, what information or characteristics about human eye tissue would you consider ideal to know in order for you to label the tissue “high quality”? (Select all that apply.)**
   - Death-to-preservation/enucleation time
   - Storage procedures
   - Patient demographics
   - Patient complaint/history of current illness
   - Patient past medical history
   - Patient family history
   - Clinical diagnosis
   - Pathological diagnosis
   - Patient treatment outcomes
   - Patient consent/authorization status
   - Quality control data on the tissue itself (e.g., use of standard operating procedures for collection, storage, and management)
   - Medications
   - Smoking history
   - Cause of death
   - Does not apply
   - Other

9. **How easy or difficult is it for you to obtain an adequate quantity of human eye tissue?**
   - Very easy
   - Easy
   - Somewhat easy
   - Somewhat difficult
   - Difficult
   - Very difficult
   - Does not apply to me

10. **How do you grade the quality of the tissue used?**
    - I image and grade it myself
    - I grade it myself, but do not image the tissue

Downloaded from iovs.arvojournals.org on 10/12/2019
11. What percentage of time is the human eye tissue you get of adequate quality for your project needs?
- Never (0%)
- Rarely (1%–25%)
- Sometimes (26%–50%)
- Often (51%–75%)
- Usually (76%–99%)
- Always (100%)
- Don’t know
- Not applicable

12. If you use fresh (non-fixed tissue) in what time frame do you need tissue prior to freezing?
- <4 hours from time of death
- 4–6 hours from time of death
- 6–10 hours from time of death
- 10–20 hours from time of death
- Other

13. What is the typical death-to-preservation/enucleation time for human eye tissue you receive?
- <6 hours
- 6–12 hours
- 12–24 hours
- 24–36 hours
- 36–48 hours
- >48 hours
- Unknown
- Does not apply

14. What is the ideal window of death-to-preservation/enucleation time for human eye tissue for your research?
- <6 hours
- 6–12 hours
- 12–24 hours
- 24–36 hours
- 36–48 hours
- >48 hours
- Unknown
- Does not apply

15. How often, if ever, have you questioned findings/outcomes from your work because you had concerns about the quality of the human eye tissue you had available to use?
- Never (0%)
- Rarely (1%–25%)
- Sometimes (26%–50%)
- Often (51%–75%)
- Usually (76%–99%)
- Always (100%)
- Don’t know
- Not applicable

16. How often, if ever, have you limited the scope of your work/objectives because of difficulty obtaining human eye tissue that met your needs?
- Never (0%)
- Rarely (1%–25%)
- Sometimes (26%–50%)
- Often (51%–75%)

17. What percentage of the human eye tissue you typically acquire for your work/objectives are you unable to use because of poor quality or other problems with the tissue itself?
- Never (0%)
- Rarely (1%–25%)
- Sometimes (26%–50%)
- Often (51%–75%)
- Usually (76%–99%)
- Always (100%)
- Don’t know
- Not applicable

Our team is exploring the possibility of developing an online resource to facilitate relationships between researchers and eye banks. Each party could post the types of tissues they either seek or can provide, along with distinguishing attributes (age, ethnicity, comorbidities, etc.). With this in mind, please answer the following question.

18. If a resource like the one described in this survey was created, how likely do you think the information provided would improve your work?
- Definitely would
- Very likely
- Somewhat likely
- Somewhat unlikely
- Very unlikely
- Definitely would not

19. Which of the following best describes the primary professional focus?
- Administrative
- Basic research
- Clinical research
- Clinical trials
- Clinical practice
- Educations/academic teaching
- In-training basic research
- In-training clinical research
- In-training clinical practice
- Surgical

20. What type of organization are you currently working in?
- Academic university
- Government
- Hospital
- Industry/Commercial/Corporate
- Nonprofit
- Private/group practice
- Retired
- Other

21. How would you classify your career stage?
- Student/predoctoral
- Postgrad/resident
- Early career up to 10 years
- Mid-career 10–25 years
- Late career 25+ years
- Post-career