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TITLE: Understanding and Supporting Public Information Needs about VCA Donation

PRINCIPAL INVESTIGATOR: Macey Henderson

CONTRACTING ORGANIZATION: Johns Hopkins University

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14. ABSTRACT

An abstract shall be provided in Block 14 and shall state the purpose, scope, and major findings and be an up-to-date report of the progress in terms of results and significance. Abstracts will be submitted to the Defense Technical Information Center (DTIC) and shall not contain proprietary information. Subject terms are keywords that may have been previously assigned to the proposal abstract or are keywords that may be significant to the research.

As the field of Vascular Composite Allotransplantation (VCA) grows, demand for VCA donations will increase. VCA donation requires separate authorization, commonly provided by deceased donors' next of kin. Therefore, the public should be educated to make informed decisions about VCA. This study aims to assess the availability and quality of existing VCA public education materials and to develop educational materials that increase public knowledge, understanding, perceptions of comfort, and willingness to donate.

To date, 1,314 public education materials have been analyzed, including materials from organ procurement organizations (OPOs), VCA centers, the Organ Procurement and Transplant Network, Veterans Affairs, the Department of Defense, and Health Resources and Services Administration. Materials included: web pages, written documents (e.g., fact sheets, research reports), and OPO Facebook and Twitter posts. Materials commonly covered upper limb (34.7%) and face (34.5%) transplants, and often referenced a specific VCA story (76.6%). Materials less commonly covered reproductive VCA (6.4%) or other VCA types (2.8%). In addition, six focus groups with members of the public have been conducted to date (n=42 total). These focus groups assessed public opinion on VCA. Analysis of these focus groups is ongoing.

Current VCA public education materials do not adequately educate the public. More comprehensive education materials are needed to prepare the public to authorize VCA donation, become potential donors, or learn about transplant options.

15. SUBJECT TERMS

- Vascular Composite Allotransplantation
- Vascular composite Allograft
- VCA
- Reconstructive transplantation
- Education
- Public opinion
- Focus groups
- Content and thematic analysis
- Delphi panel
- Qualitative research

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- 1. INTRODUCTION:** *Narrative that briefly (one paragraph) describes the subject, purpose and scope of the research.*

As the field of Vascular Composite Allotransplantation (VCA) grows, demand for VCA donations will increase. VCA donation requires separate authorization, commonly provided by deceased donors' next of kin. Therefore, the public should be educated to make informed decisions about VCA. This study aims to assess the availability and quality of public information about VCA donation, and to develop educational materials to increase public knowledge of and comfort with VCA.

- 2. KEYWORDS:** *Provide a brief list of keywords (limit to 20 words).*

Vascular Composite Allotransplantation
Vascular composite Allograft
VCA
Reconstructive transplantation
Education
Public opinion
Focus groups
Content and thematic analysis
Delphi panel
Qualitative research

- 3. ACCOMPLISHMENTS:** *The PI is reminded that the recipient organization is required to obtain prior written approval from the awarding agency grants official whenever there are significant changes in the project or its direction.*

What were the major goals of the project?

List the major goals of the project as stated in the approved SOW. If the application listed milestones/target dates for important activities or phases of the project, identify these dates and show actual completion dates or the percentage of completion.

Major Task 1: Prepare Regulatory Documents

- Milestone: IRB and HRPO approval at Johns Hopkins
- Milestone: IRB and HRPO approval at NU
Timeline: 6 months, 100% complete

Major Task 2: Coordinate and Train Study Staff in Qualitative Research

- Milestone: Research staff hired and trained in qualitative research
Timeline: 6 months, 100% complete

Specific Aim 1: To assess the availability and quality of information about VCA donation delivered through state and federally sponsored online registries, DoD/VA entities, and public awareness materials.

Major Task 3: Content Analysis of Available VCA Donation Education

- Milestone: content analysis of existing educational materials
Timeline: 12 months, 95% complete
- Milestone: report findings from content analysis
Timeline: 12 months, 20% complete

Major Task 4: Focus Groups with Members of the Public

- Milestone: schedule 1st focus group, consent participants
Timeline: 9 months 100% complete
- Milestone: conduct 3 focus groups at each site
Timeline: 12 months 83% complete

Major Task 5: Analyze Qualitative Data

- Milestone: Report findings from focus groups
Timeline: 14 months 0% complete

Specific Aim 2: To develop educational materials that increase public knowledge, understanding, perceptions of comfort, and willingness to donate.

Major Task 6: Develop Educational Materials for VCA

- Milestone: create educational materials, social media strategy, and media toolkit
Timeline: 16 months 0% complete

Major Task 7: Conduct Delphi Panel

- Milestone: report results from data analysis
Timeline: 24 months 0% complete
- Milestone: Write manuscript detailing the results of the consensus reached through the Delphi method
Timeline: 24 months 0% complete

Major Task 8: Conduct Focus Groups about Developed VCA Education

- Milestone: schedule 1st focus group, consent participants
Timeline: 26 months 0% complete
- Milestone: conduct 3 focus groups at each site
Timeline: 26 months 0% complete

Major Task 9: Conduct Further Usability Testing via Donate Life America

- Milestone: launch social media strategy from the Donate Life America social media channels (Facebook, Twitter, Instagram)
Timeline: 32 months 0% complete
- Milestone: manuscript preparation/submission for publication report 0% complete

What was accomplished under these goals?

For this reporting period describe: 1) major activities; 2) specific objectives; 3) significant results or key outcomes, including major findings, developments, or conclusions (both positive and negative); and/or 4) other achievements. Include a discussion of stated goals not met. Description shall include pertinent data and graphs in sufficient detail to explain any significant results achieved. A succinct description of the methodology used shall be provided. As the project progresses to completion, the emphasis in reporting in this section should shift from reporting activities to reporting accomplishments.

Major Task 1: Prepare Regulatory Documents – **100% complete**

- Milestone: IRB and HRPO approval at Johns Hopkins
- Milestone: IRB and HRPO approval at NU

Major Task 2: Coordinate and Train Study Staff in Qualitative Research – **100% complete**

- Subtask1: Hiring and Training of Study Staff

Major Task 3: Content Analysis of Available VCA Donation Education

- Subtask 1: Developed rules for coding educational content text and images
- Subtask 2: Performed a comprehensive search of all VCA education materials currently provided by organ procurement organizations (n=58), national advocacy organizations, and each state’s Department of Motor Vehicles (n=50), VA, DOD, hospital, UNOS, some OPOs (n=28) - **100% complete**
- Subtask 3: Coded the content using content analysis (text and images). 1,314 documents were coded as of 9/29/2019 - **100% complete**
- Synthesized the coded segments for themes and patterns - **90% complete**

Major Task 4: Focus Groups with Members of the Public

- Northwestern: Three focus groups have been conducted: focus group #1 (n=7), #2 (n=11), #3 (n=9). Focus group #1 and #2 and #3 have been transcribed - **100% complete**
- Johns Hopkins: Three focus groups have been conducted: focus group #1 (n=6*), #2 (n=7), #3 (n=2). However, n=2 does not adequately meet focus group design, so we will be conducting an additional focus group to reach target sample size (n=30/site). Focus groups #1 and #2 have been transcribed - **66% complete**.

**(n=2) did not complete the study, (n=1) showed up late and answered questions separately*

Preliminary Results from Major Task 3, Subtask 3

- 1,314 public education materials were analyzed, including Facebook posts (61.6%), Twitter posts (29.9%), websites (6.4%), and written documents (2.1%).
- Upper limb (34.7%) and face (34.5%) transplants were more commonly addressed than reproductive (6.4%) or other VCA types (2.8%).
- Most materials (76.6%) referenced a specific VCA story.
- Social media posts generally described VCA stories as “inspiring,” “amazing,” and “beautiful.”
- Few materials described which patient population could benefit from VCA (e.g., Veterans, amputees, burn victims, 16.4%), the authorization requirements for VCA donation (6.6%), the rehabilitation process (2.2%) the appearance of transplanted VCA organs (1.2%), or the VCA candidate selection processes (0.4%).
- Current VCA public education materials do not adequately educate the public. More comprehensive education materials are needed to prepare the public to authorize VCA donation, become potential donors, or learn about transplant options.

Discussion of stated goals not met

- While both centers have held three focus groups, the third focus group at Johns Hopkins had only 2 participants. Johns Hopkins will hold a fourth focus group during the next quarterly reporting period in order to reach sufficient participation.
 - All existing educational documents were coded during this reporting period. The study team decided to also include social media posts from organ procurement organizations, greatly increasing the number of materials to code. This was a lengthy process but allowed us to capture how VCA is presented to the public on social media platforms. We aim to complete the synthesis of coded materials within the next quarterly reporting period.

What opportunities for training and professional development has the project provided?

If the project was not intended to provide training and professional development opportunities or there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe opportunities for training and professional development provided to anyone who worked on the project or anyone who was involved in the activities supported by the project. “Training” activities are those in which individuals with advanced professional skills and experience assist others in attaining greater proficiency. Training activities may include, for example, courses or one-on-one work with a mentor. “Professional development” activities result in increased knowledge or skill in one’s area of expertise and may include workshops, conferences, seminars, study groups, and individual study. Include participation in conferences, workshops, and seminars not listed under major activities.

The study team at Northwestern and Johns Hopkins were trained in qualitative research methods, including the design and facilitating of focus groups and the analysis of qualitative data.

How were the results disseminated to communities of interest?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe how the results were disseminated to communities of interest. Include any outreach activities that were undertaken to reach members of communities who are not usually aware of these project activities, for the purpose of enhancing public understanding and increasing interest in learning and careers in science, technology, and the humanities.

The content analysis of existing educational materials was presented as a poster at the American Transplant Congress:

Henderson M, Van Pilsum Rasmussen S, Uriarte J Anderson N, Doby B, Cooney C, Brandacher G, Segev D, Gordon E. “The Scope and Limitations of Current Public Education Materials on Vascular Composite Allotransplantation and Donation in the United States.” American Transplant Congress. Boston MA, 2019.

What do you plan to do during the next reporting period to accomplish the goals?

If this is the final report, state “Nothing to Report.”

Describe briefly what you plan to do during the next reporting period to accomplish the goals and objectives.

During the next year we aim to:

- Finish conducting focus groups with members of the public
- Complete the synthesis of coded segments of existing education materials
- Report findings from content analysis
- Analyze qualitative data from focus groups
- Report findings from focus groups at professional conferences and in a publication
- Develop new educational materials on VCA
- Hold a Delphi panel regarding new educational materials

4. **IMPACT:** *Describe distinctive contributions, major accomplishments, innovations, successes, or any change in practice or behavior that has come about as a result of the project relative to:*

What was the impact on the development of the principal discipline(s) of the project?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe how findings, results, techniques that were developed or extended, or other products from the project made an impact or are likely to make an impact on the base of knowledge, theory, and research in the principal disciplinary field(s) of the project. Summarize using language that an intelligent lay audience can understand (Scientific American style).

The experience of analyzing the public education materials provided new insights into how VCA is conceptualized and represented in very limited ways by OPOs and other news sources. This means that there is a great opportunity to expand and refine upon educational materials for the public to learn about VCA as a treatment option. Specifically, our finding that most of the public education materials presented a highly optimistic view of VCA reinforces the need for a balanced, neutral presentation of information about VCA for the public, which further supports Dr. Henderson’s public education materials and Dr. Gordon’s website development. The experience of moderating focus groups with members of the public revealed important knowledge deficits that should be addressed in order for the public to understand basic VCA transplantation. For example, some members of the public desired donating a VCA organ *after* a funeral, which reflected both (a) a lack of knowledge about the time-limited process of organ retrieval and implantation, and (b) a strong concern with funeral preparations and the emotional implications for families of seeing their deceased loved ones not whole. Additionally, members of the focus group often asked questions about topics that were rarely covered in the educational materials including appearance, authorization and rehabilitation. Thus, our educational materials will directly address these and other related emerging concerns.

What was the impact on other disciplines?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe how the findings, results, or techniques that were developed or improved, or other products from the project made an impact or are likely to make an impact on other disciplines.

Preliminary review of focus group transcriptions suggests that participants had religious concerns that may be barriers to VCA donation and receptivity to VCA. We will explore these and cultural factors in the forthcoming qualitative analysis phase

What was the impact on technology transfer?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe ways in which the project made an impact, or is likely to make an impact, on commercial technology or public use, including:

- *transfer of results to entities in government or industry;*
- *instances where the research has led to the initiation of a start-up company; or*
- *adoption of new practices.*

Nothing to Report

What was the impact on society beyond science and technology?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe how results from the project made an impact, or are likely to make an impact, beyond the bounds of science, engineering, and the academic world on areas such as:

- *improving public knowledge, attitudes, skills, and abilities;*
- *changing behavior, practices, decision making, policies (including regulatory policies), or social actions; or*
- *improving social, economic, civic, or environmental conditions.*

The method of data collection for this study naturally promotes dissemination of information. Through the process of recruitment for our focus groups, we raised awareness about the option of VCA by handing out flyers. Through the process of conducting the focus groups, we educated the public about what VCA is, the types of VCA, how VCA works, in order to learn more about public perceptions.

5. CHANGES/PROBLEMS: *The PD/PI is reminded that the recipient organization is required to obtain prior written approval from the awarding agency grants official whenever there are significant changes in the project or its direction. If not previously reported in writing, provide the following additional information or state, "Nothing to Report," if applicable:*

Nothing to Report

Actual or anticipated problems or delays and actions or plans to resolve them

Describe problems or delays encountered during the reporting period and actions or plans to resolve them.

Nothing to Report

Changes that had a significant impact on expenditures

Describe changes during the reporting period that may have had a significant impact on expenditures, for example, delays in hiring staff or favorable developments that enable meeting objectives at less cost than anticipated.

Nothing to Report

Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents

Describe significant deviations, unexpected outcomes, or changes in approved protocols for the use or care of human subjects, vertebrate animals, biohazards, and/or select agents during the reporting period. If required, were these changes approved by the applicable institution committee (or equivalent) and reported to the agency? Also specify the applicable Institutional Review Board/Institutional Animal Care and Use Committee approval dates.

Significant changes in use or care of human subjects

Nothing to Report

Significant changes in use or care of vertebrate animals

Nothing to Report

Significant changes in use of biohazards and/or select agents

Nothing to Report

6. PRODUCTS: *List any products resulting from the project during the reporting period. If there is nothing to report under a particular item, state "Nothing to Report."*

- **Publications, conference papers, and presentations**

Report only the major publication(s) resulting from the work under this award.

Journal publications. *List peer-reviewed articles or papers appearing in scientific, technical, or professional journals. Identify for each publication: Author(s); title; journal; volume; year; page numbers; status of publication (published; accepted, awaiting publication; submitted, under review; other); acknowledgement of federal support (yes/no).*

Nothing to Report

Books or other non-periodical, one-time publications. *Report any book, monograph, dissertation, abstract, or the like published as or in a separate publication, rather than a periodical or series. Include any significant publication in the proceedings of a one-time conference or in the report of a one-time study, commission, or the like. Identify for each one-time publication: author(s); title; editor; title of collection, if applicable; bibliographic information; year; type of publication (e.g., book, thesis or dissertation); status of publication (published; accepted, awaiting publication; submitted, under review; other); acknowledgement of federal support (yes/no).*

Nothing to Report

Other publications, conference papers and presentations. *Identify any other publications, conference papers and/or presentations not reported above. Specify the status of the publication as noted above. List presentations made during the last year (international, national, local societies, military meetings, etc.). Use an asterisk (*) if presentation produced a manuscript.*

Henderson M, Van Pilsum Rasmussen S, Uriarte J Anderson N, Doby B, Cooney C, Brandacher G, Segev D, Gordon E. "The Scope and Limitations of Current Public Education Materials on Vascular Composite Allotransplantation and Donation in the United States." American Transplant Congress. Boston MA, 2019.

- **Website(s) or other Internet site(s)**

List the URL for any Internet site(s) that disseminates the results of the research activities. A short description of each site should be provided. It is not necessary to include the publications already specified above in this section.

Nothing to Report

- **Technologies or techniques**

Identify technologies or techniques that resulted from the research activities. Describe the technologies or techniques were shared.

Nothing to Report

- **Inventions, patent applications, and/or licenses**

Identify inventions, patent applications with date, and/or licenses that have resulted from the research. Submission of this information as part of an interim research performance progress report is not a substitute for any other invention reporting required under the terms and conditions of an award.

Nothing to Report

- **Other Products**

Identify any other reportable outcomes that were developed under this project. Reportable outcomes are defined as a research result that is or relates to a product, scientific advance, or research tool that makes a meaningful contribution toward the understanding, prevention, diagnosis, prognosis, treatment and /or rehabilitation of a disease, injury or condition, or to improve the quality of life. Examples include:

- *data or databases;*
- *physical collections;*
- *audio or video products;*
- *software;*
- *models;*
- *educational aids or curricula;*
- *instruments or equipment;*
- *research material (e.g., Germplasm; cell lines, DNA probes, animal models);*
- *clinical interventions;*
- *new business creation; and*
- *other.*

Nothing to Report

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Provide the following information for: (1) PDs/PIs; and (2) each person who has worked at least one person month per year on the project during the reporting period, regardless of the source of compensation (a person month equals approximately 160 hours of effort). If information is unchanged from a previous submission, provide the name only and indicate “no change”.

Example:

Name: Mary Smith
 Project Role: Graduate Student
 Researcher Identifier (e.g. ORCID ID): 1234567
 Nearest person month worked: 5

Contribution to Project: Ms. Smith has performed work in the area of combined error-control and constrained coding.

Funding Support: The Ford Foundation (Complete only if the funding support is provided from other than this award.)

Name: Sarah Rasmussen
 Project Role: Research Data Analyst
 Researcher Identifier (e.g. ORCID ID): 0000-0002-4644-3590
 Nearest person month worked: 1.2 Calendar Months
 Contribution to Project: Content analysis of VCA materials

Name: Brianna Doby
 Project Role: Research Assistant
 Nearest person month worked: (uncompensated effort)
 Contribution to Project: Content analysis of VCA materials

Name: Macey Henderson
 Project Role: Principal Investigator
 Researcher Identifier (e.g. ORCID ID): 0000-0002-4239-1252
 Nearest person month worked: 1.2 Calendar Months
 Contribution to Project: Oversight of all research activities

Name: Dorry Segev
 Project Role: Co-Investigator
 Researcher Identifier (e.g. ORCID ID): 0000-0002-1924-4801
 Nearest person month worked: 0.6 Calendar Months
 Contribution to Project: Oversight of all research activities

Name: Jeffrey Kahn
 Project Role: Co-Investigator
 Nearest person month worked: 0.12 Calendar Months
 Contribution to Project: Oversight of research activities

Name: Jefferson Uriarte
Project Role: Research Study Coordinator
Researcher Identifier (e.g. ORCID ID): 0000-0002-8507-963X
Nearest person month worked: 6 Calendar months
Contribution to Project: Content analysis of VCA materials, subject recruitment, transcription, assisted in conducting 3 focus groups

Name: Naomi Anderson
Project Role: Research Study Coordinator
Researcher Identifier (e.g. ORCID ID): 0000-0002-8991-9739
Nearest person month worked: 6 Calendar months
Contribution to Project: Content analysis of VCA materials, subject recruitment, transcription, assisted in conducting 3 focus groups

Name: Elisa Gordon
Project Role: Partnering Principal Investigator
Researcher Identifier (e.g. ORCID ID): 0000-0003-0969-1998
Nearest person month worked: 1.8 Calendar months
Contribution to Project: Study Oversight at Northwestern, guided VCA material content analysis, moderated 3 focus groups

Name: Gerald Brandacher
Project Role: Partnering Principal Investigator
Researcher Identifier (e.g. ORCID ID): 0000-0001-7790-441X
Nearest person month worked: 1.2 Calendar Months
Contribution to Project: Oversight of all research activities

Name: Carisa Cooney
Project Role: Co-investigator, Research Manager
Researcher Identifier (e.g. ORCID ID): 0000-0002-5475-206X
Nearest person month worked: 1.2 Calendar Months
Contribution to Project: Oversight of regulatory approvals

Name: Jaimie Shores
Project Role: Co-investigator
Nearest person month worked: 0.36 Calendar Months
Contribution to Project: Oversight of regulatory approvals

Name: Hannah Sung
Project Role: Research Data Analyst
Nearest person month worked: 12 Calendar months
Contribution to Project: Moderation of focus groups, preparation for qualitative analysis

Name: Alex Ferzola
Project Role: Research Program Assistant
Nearest person month worked: 12 Calendar Months
Contribution to Project: Moderation of focus groups, study coordination

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

If the active support has changed for the PD/PI(s) or senior/key personnel, then describe what the change has been. Changes may occur, for example, if a previously active grant has closed and/or if a previously pending grant is now active. Annotate this information so it is clear what has changed from the previous submission. Submission of other support information is not necessary for pending changes or for changes in the level of effort for active support reported previously. The awarding agency may require prior written approval if a change in active other support significantly impacts the effort on the project that is the subject of the project report.

Nothing to Report

What other organizations were involved as partners?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe partner organizations – academic institutions, other nonprofits, industrial or commercial firms, state or local governments, schools or school systems, or other organizations (foreign or domestic) – that were involved with the project. Partner organizations may have provided financial or in-kind support, supplied facilities or equipment, collaborated in the research, exchanged personnel, or otherwise contributed.

Provide the following information for each partnership:

Organization Name:

Location of Organization: (if foreign location list country)

Partner’s contribution to the project (identify one or more)

- *Financial support;*
- *In-kind support (e.g., partner makes software, computers, equipment, etc., available to project staff);*
- *Facilities (e.g., project staff use the partner’s facilities for project activities);*
- *Collaboration (e.g., partner’s staff work with project staff on the project);*
- *Personnel exchanges (e.g., project staff and/or partner’s staff use each other’s facilities, work at each other’s site); and*
- *Other.*

Nothing to report

8. SPECIAL REPORTING REQUIREMENTS

COLLABORATIVE AWARDS: *For collaborative awards, independent reports are required from BOTH the Initiating Principal Investigator (PI) and the Collaborating/Partnering PI. A duplicative report is acceptable; however, tasks shall be clearly marked with the responsible PI and research site. A report shall be submitted to <https://ers.amedd.army.mil> for each unique award.*

QUAD CHARTS: *If applicable, the Quad Chart (available on <https://www.usamraa.army.mil>) should be updated and submitted with attachments.*

9. **APPENDICES:** *Attach all appendices that contain information that supplements, clarifies or supports the text. Examples include original copies of journal articles, reprints of manuscripts and abstracts, a curriculum vitae, patent applications, study questionnaires, and surveys, etc.*

Appendix 1: Abstract accepted at American Transplant Congress

Appendix 2: Aim 1 Focus Group Guide: Public Opinion on VCA and Existing Education Materials

Appendix 1:

The Scope and Limitations of Current Public Education Materials on Vascular Composite Allotransplantation and Donation in the United States

Author Block

Macey Henderson, Sarah Rasmussen, Jefferson Uriarte, Naomi Anderson, Brianna Doby, Carisa Cooney, Gerald Brandacher, Dorry Segev, Elisa Gordon
Johns Hopkins University
Northwestern University

Abstract:

***Purpose:** As the field of Vascular Composite Allotransplantation (VCA) evolves and more VCAs are performed, the demand for VCA donations will increase. However, the public has little awareness and knowledge of VCA. Further, donation requires specific and separate authorization from other solid organs, commonly provided by the deceased donor's next of kin. Therefore, it is essential for the public to be educated to make informed decisions about VCA.

***Methods:** VCA educational materials were obtained from organ procurement organizations, VCA transplant programs, the United Network for Organ Sharing, Health Services and Resources Administration, Veterans' Affairs, and the Department of Defense. Materials included web pages, videos, and written documents. Content analysis was performed on all educational materials to identify key topics covered in VCA education.

***Results:** A total of 30 educational materials were identified and analyzed. Preliminary analysis found that materials regularly covered hand and face transplants, but not other types of VCA. Materials commonly positioned Wounded Warriors, burn victims, and individuals who have lost upper extremity limbs as the target population for VCA, and presented stories of VCA recipients. VCA was commonly described as "groundbreaking," "innovative," and "life-giving," and the surgical process as "complex" and "complicated." VCA was touted as "a treatment," "experimental," or "research" by various documents.

The "potential to dramatically improve" and restore a VCA recipient's mental and physical health by regaining the ability to "perform daily activities" and by improving body-image were generally covered, along with the long-term requirements of immunosuppression and rehabilitation. However, materials varied in their coverage of donation authorization, risks of VCA, and VCA eligibility. Materials seldom discussed the regulatory bodies overseeing VCA, the allocation of VCA organs, the patient evaluation process, and post-operative recovery. The extent of donor and recipient resemblance after VCA was rarely addressed.

***Discussion:** Our findings suggest that educational materials sufficiently address hand and face transplants, but insufficiently address other VCA types. Further, materials inconsistently covered key topics important for decision-making. Given the specific authorization required for VCA donation, public educational materials on VCA should standardize content so that potential donor families receive consistent, comprehensive, and accurate information for informed decision making.

Learning Objective: To describe content covered and limitations of current public education materials about VCA transplantation and donation

Appendix 2: Aim 1 Focus Group Guide: Public Opinion on VCA and Existing Education Materials

VCA stands for Vascular Composite Allotransplantation. Examples of VCA include hand, arm, or face transplants. In VCA, a recipient would receive a hand, arm or face transplant from a deceased donor, someone who has passed away.

1. Has anyone heard of these types of transplants before?
 - a. If so, where had you heard of it?
2. Based on what you've heard about them before, or on what you've learned today, what do you think about VCA transplants?
3. When you think about hand, limb or face transplants, what words come to mind?
4. Is anyone here a registered organ donor? You might have registered as an organ donor when you got your driver's license, on your phone or on Facebook.
5. How do you feel about the idea of being a hand, or face donor?
 - a. Would you donate those parts of your body?
 - b. What would motivate you to donate them?
 - c. What are your reservations about it?
6. What topics should be added?
7. What information do you like?
8. When/where would you want to learn more about VCA – at what times or places would it be good/appropriate to learn more about VCA? At what times or places would it be bad/inappropriate to learn more about VCA?
9. Hand, arm, and face transplants are often used to help people who have been injured in accidents, such as veterans. Would you want to know more about the people who receive hand, arm, and face transplants?
10. What else would you want to know about VCA?
11. We plan to improve the way people are educated about hand, limb, and face transplants. What other suggestions do you have for educating the public about VCA?