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A Community-Driven Intervention for Improving Bio-Specimen Donation in African American Communities

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Abstract

Introduction—Human bio-specimens are an invaluable resource for addressing cancers and other chronic diseases. The purpose of this study was to assess the impact of an educational intervention on bio-specimen knowledge and attitudes.

Methods—The participants consisted of 112 African Americans, 18 years and older, and who had not provided bio-specimens for any health related research in the past. A total of 55 participants received the educational brochure and 57 received the educational video. The main outcomes of the study were knowledge and attitudes for bio-specimen donation. This information was collected pre-and-post intervention.

Results—The average knowledge scores increased ($p < 0.0001$) and the average attitude scores for bio-specimen donation improved ($p < 0.0001$) post intervention for both the video and brochure conditions. There was an interaction between the intervention condition and knowledge where the participants who received the educational video showed a greater increase in knowledge pre-to-post compared to those who received the educational brochure ($p = 0.0061$). There were no significant interactions between the two intervention conditions for attitudes towards bio-specimen donation.

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Conflict of Interest: Author Patel, Author Inman, Author Gishe, Author Johnson, Author Brown, Author Kanu, Author Theriot, Author Sanderson, Author Hull and Author Hargreaves declare that they have no conflict of interest.

Informed Consent: This research was approved by the Meharry Medical College and Tennessee State University Review Boards and each participant underwent a process of informed consent emphasizing the voluntary nature of participation, the randomization process, and the procedures they will undergo (completing a pre-intervention and post-intervention).

Animal Studies: No animal studies were carried out by the authors for this article.

Discussion—The results of this study demonstrated the feasibility and efficacy of an academic institution collaborating with the African American community in developing educational tools for bio-specimen donation.

Keywords

Bio-specimen Education; African Americans; Community Driven; Behavioral Intervention

Background

There is increasing scientific consensus about the value of research in studying human bio-specimens. The advancement of storing (biobanks) and studying human bio-specimens is one of the critical resources in the development of more effective tools to prevent, diagnose, and treat a variety of diseases and conditions [1, 2]. Specimens such as blood and tissue are essential resources in the advancement of genetic and biomedical technologies and in the development of more effective tools to address a variety of diseases [3]. Biobanking services have been identified as one of the key areas to accelerate the discovery and development of new drugs. Bio-specimens are banked in three different models, Prospective, Retrospective, and Clinical Trials [4]. The National Cancer Institute has provided a comprehensive articulation of best practices for bio-specimen use which allows clinicians, scientists, ethicists, and other biotechnical research experts, advocates, and pharmaceutical professionals to promote consistency and encourage quality in biobank use [5]. Prospective collections allow bio-specimen samples to be collected in an effort to meet the investigator's specific requirements. Retrospective collection provides bio-specimens that are collected because they have a potential interest to researchers in the future. Clinical trial bio-specimens are collected specifically for clinical trials that are relevant only to the investigator. Many epidemiologic studies have started to incorporate the collection of bio-specimens as part of their population-based health investigations [6, 8].

While biobanks are readily accessible for clinical and research purposes and have the potential for increasing improved outcomes for treatments and therapies, especially those that are more prevalent among minorities; these same populations have a considerably lower participation rate in medical research which includes bio-specimen collection activities [9–11]. Scientists remain challenged by inequitable access to bio-specimens from racial and ethnic minorities [12]. Researchers must be provided with adequate representation of bio-specimens of those most affected by the disparities in order to improve the generalizability of clinical trial results and reduce challenges to investigators to address gaps in substantial research regarding these disparities [13]. There is a significant amount of research available on the perceptions, attitudes, and knowledge about the donation of bio-specimens [14, 15]. The use of bio-specimens in research contributes to the novel preventative, diagnostic, and therapeutic interventions used by clinicians to address current and future research questions [16].

While significant efforts are ongoing to educate the scientific community about the merits of bio-specimen research, efforts must be increased to encourage public support and participation in bio-specimen donation, especially among under-represented communities

[17, 18]. Research has shown that multi-ethnic biobanking which ensures high-quality human bio-specimen data must consider the cultural sensitivities of diverse communities in order to improve collection efforts [19–21]. Support has been available at the community level to educate individuals and increase awareness regarding prospective, retrospective, and clinical trial biobanking benefits. Strong community outreach supports bio-specimen awareness in research and treatment. Understanding the relevance of bio-specimen collection efforts in diverse populations, including rural areas, leverages the strengths of bio-specimen research in many disciplines including cancer research. On the national level, support is available to develop a strong bio-specimen repository populated with a significant proportion of available bio-specimens from all racial and ethnic groups. A collaborative national system is only viable if under-represented members of low income and disparate populations regard health disparate problems associated with bio-specimen collections and significantly participate in bio-specimen donation.

Each year, African Americans and other ethnic and racial minorities account for fewer cases of diagnosed cancers, while accounting for more cases of advanced diagnoses, resulting in lower survival rates for many types of cancers [22]. Some examples include higher breast cancer mortalities among African Americans when compared to Caucasian women [23, 24]. The current research suggests that there are differences in risk and prognostic factors, evidence-based research is limited [25]. Research reflecting the relatively small participation of minority populations could be exponentially improved by increasing the percentage of minorities donating to biobanks to allow a more thorough assessment of associations of diagnostic procedures, including rapid case ascertainment, treatment procedures, established risk factors, genetic susceptibility, characterization of tumor biology, and socioeconomic factors [26, 27]. Increased participation by ethnic and racial minorities in case-control studies would reduce selection bias that results from low participation rates [28, 29]. This has been a significant topic of concern and discussed repeatedly in the literature [30–34].

The short-term goals of this study are to understand, educate, and improve the knowledge, attitudes, and behavioral intent of African Americans about donating bio-specimens for cancer research. The long-term goal is to improve bio-specimen donations and collection rates from African Americans.

Methods

Participants were recruited face-to-face from the lobby area of Matthew Walker Comprehensive Health Center (MWCHC) located in Nashville, Tennessee. MWCHC is a federally funded (Health Resources and Services Administration) community health center that serves primarily low-income communities. MWCHC serves more than 18,000 patients a year and the majority of their patient population is African American, uninsured, and have an annual household income of \$15,000. In addition, participants were recruited through flyers posted at community businesses and community centers. These flyers provided a brief description of the study, eligibility criteria for participation, and a number to call for those who are interested in participating in the study. The recruitment was conducted by lay community educators who were trained to screen for study eligibility. The eligibility criteria included being at least 18 years of age, self-identified as African American, and those who

have not provided bio-specimens for any health related research in the past. A series of workshops were conducted by the study investigators to train the lay community educators to recruit eligible participants, obtain written informed consent, administer the assessments, and deliver the intervention.

The intervention consisted of a brochure and a video. Study participants underwent a blocked random assignment such that they were randomly assigned to be in either of the two interventions. Blocking occurred by gender and the age groups of 18–39 and 40 years and older. The rationale for this procedure was to ensure that there is equal representation between the groups in the two intervention conditions based on the characteristics. The intervention and study assessments were delivered in a room at MWCHC.

The intervention consisted of either receiving an educational brochure about bio-specimen donation or watching the 11 minutes video about collecting and donating bio-specimens. This research was approved by the Internal Review Boards of the Meharry Medical College and Tennessee State University. Participants were required to complete a pre and post assessment questionnaire. Each participant underwent a process of informed consent emphasizing the voluntary nature of participation, the randomization process, and the procedures they will undergo (completing a pre-intervention and post-intervention). Participants received \$35 in cash after completing the post assessment.

Intervention Development

Community Based Participatory Research (CBPR) principles provided the guidelines for intervention development. CBPR is a research approach that involves partnerships between experts and community members. The community members are involved in all stages of research including planning, development, implementation, evaluation, and dissemination. There are nine principles of the CBPR that guide partnerships between experts and the community [35].

Three focus groups were conducted to develop a catalog of barriers to bio-specimen donation. The first focus group consisted of self-identified African American men and the second focus group consisted of African American women, 18 years and older. The final focus group consisted of healthcare professionals and cancer researchers. The rationale for these focus groups was to gain insight and understanding of the barriers to bio-specimen from the perspective of the community and professionals. This information along with the brochure on bio-specimen donation published by the National Cancer Institute was used to develop the interventional brochure and video.

The focus groups were conducted at MWCHC and moderated by the project coordinator. The moderator was selected because he was a member of the target community, and had experience moderating focus groups in past community-based projects. The moderator was provided with a list of “probes” to facilitate the discussions. Each participant provided informed consent prior to their participation, including an agreement (or refusal) to be videotaped and audiotaped during the sessions. Participants were also asked to provide permission to be contacted if they were selected to be on the Community Advisory Board (CAB).

The CAB consisted of six members and they collaborated with the development of an educational brochure and video. CAB members provided informed consent prior to their participation. Three CAB sessions were used to develop the educational brochure and video. CAB members provided guidance on the content and language of the brochure and video. The CAB members role was only to provide inputs on the content, language and look of the educational tools (brochure and video). The rationale for collaborating with the CAB was to insure that the intervention was culturally tailored and easy to read and understand.

Intervention: Data Collection, Coding, and Analysis

The primary outcomes of interest were knowledge and attitudes about bio-specimen donation. Knowledge about bio-specimens was assessed by a summative score of an 8-item dichotomously (True/false) scored scale and attitudes about bio-specimen donation was assessed by summative score of a 6-item dichotomously (True/false) scored scale. An example of a knowledge item is “I understand the risk of donating bio-specimens” and “I do not trust medical researchers with my bio-specimens”, this is an example of an attitude item. Both of these scales were developed by Dr. Patel in collaboration with the African American community, researchers in cancer biology, and health educators. These scales had adequate reliability (knowledge scale Cronbach’s alpha = .82; attitude scale Cronbach’s alpha = .72). The responses on these two scales were summed to provide an overall knowledge and attitude score. The maximum knowledge score was 8 and the maximum attitude score was 12, with the higher scores on both scales representing greater knowledge and better attitude towards donating.

Data Analysis

Chi-square tests for categorical variables, CMH for ordinal variables and Wilcoxon rank-sum test for continuous variables were used to examine the difference between demographic, lifestyle characteristics, knowledge and attitude of the participants by screening status at pre intervention. A multivariate analysis of variance (MANOVA) was used to evaluate the associations between pre- and post-intervention scores in knowledge and attitudes screening status. To adjust for potential confounding variables, key demographic variables (age, gender, marital status, education and income) were controlled. None of the demographic variables were statistically significant and not included in the final model. The outputs for this manuscript were generated using SAS software for Windows, Version 9.4, a product of SAS Institute Inc., Cary, North Carolina, USA. All the P-values were based on two-sided probability tests.

Results

Demographic and Lifestyle Characteristics

The interventions, as well as pre- and post-intervention interviews, were delivered to 112 African Americans, resident of Nashville, Tennessee, 55 of whom got the educational brochure and 57 received the educational video. Demographic and lifestyle characteristics of the study participants are presented in Table 1. There were no significant differences between the groups that received the brochure versus the group who received the video. The majority of participants had a high school education (36.6%), were divorced/widowed/

separated or never married (60.7%), and had an annual household income of \$25,000 or more (44.1%). In addition, a larger percentage of participants reported their health as excellent to good (77.7%), had health insurance (72.3%), and an intention to donate bio-specimens in the future after receiving the intervention (pre = 86.4%; post = 90.8%).

Relationship between Information Method and Bio-Specimen Knowledge Scores

There was a main effect for bio-specimen knowledge scores indicating that participants knowledge about donating bio-specimens increased from pre-intervention to post-intervention ($F(1,110) = 217.12, p < 0.0001$). There was also a main effect for information method indicating that participants who received the educational video had greater knowledge about donating bio-specimens compared to participants who received the educational brochure ($F(1, 110) = 5.87, p = 0.0170$). There was a significant interaction between bio-specimen knowledge scores and information methods ($F(1,110) = 7.82, p < 0.0061$). As seen in Figure 1, there was a greater increase in average bio-specimen knowledge scores from pre-intervention to post-intervention for participants who received the educational video compared to those who received the educational brochure.

Relationship between Information Method and Bio-Specimen Attitude Scores

There was a main effect for bio-specimen attitude scores indicating that participants had more positive attitudes about donating bio-specimens from pre-intervention to post-intervention ($F(1,110) = 78.56, p < 0.0001$). There was not significant main effect for information method indicating that either receiving the educational video or brochure did not have an effect on participants attitudes about donating bio-specimens ($F(1,110) = 0.06, p = 0.8085$). Also, there was not significant interaction between attitudes and the information method ($F(1,110) = 0.31, p = 0.5817$).

Discussion

The hypothesis regarding the relationship between educational tools and knowledge was supported. The participants showed an increase in knowledge about bio-specimen donation after receiving the educational intervention via video or brochure. The findings of this study are supported by others that have used educational brochures and videos to increase knowledge about a variety of health conditions [36–38].

There was an interaction between the information method and knowledge that the participants who received the educational video demonstrated a greater increase in knowledge pre-to-post compared to those who received the educational brochure. Health information can be supplied via a variety of mediums, such as, videos, brochures, web-based, and face-to-face. There is a growing body of literature that has indicated that providing information via a video is more effective at increasing health knowledge in the short-term than providing a pamphlet or brochure alone [39, 40]. The proponents of using digital/video formats have argued that using digital media is efficacious because it is a less intensive means of delivering information. The information can be modified quickly, and the information can be administered in many digital formats, such as, DVDs, streaming videos and so on, hence a broader audience can be reached quicker. The proponents for print

medium have argued that written materials allow participants to review information at their own pace, information in this format can be reviewed easier, and there are a number of people who may not have digital media access or may not have the basic skills to use digital media [41, 42].

The hypothesis regarding the relationship between educational tools and attitudes was supported. Participants showed a more positive attitude about bio-specimen donation after receiving the educational intervention via video or brochure. The findings of this study are supported with the findings of others who have used educational brochures and videos to improve attitudes about a variety of health conditions [43, 44].

There were no differences in the improvement of attitudes between the video condition and the brochure condition. A potential explanation for the lack of differential impact of video versus brochure conditions on attitudes about bio-specimens is the tailoring of information culturally. The target community was a partner in creating the content and determining the language and presentation of the bio-specimen donation information for both the video and brochure conditions. Previous research has indicated that culturally tailoring health information leads to more positive attitudes towards changing health behaviors compared to not tailoring the information. It could be that culturally tailoring bio-specimen donation information may remove any effects that the medium of presentations may have [45, 46].

Conclusion

This study demonstrated effectiveness of culturally sensitive educational tools to improve bio-specimen donation knowledge and attitudes. The target group was African Americans, a group that carries a disproportionate burden for many cancers and other chronic diseases. The information gathered and the study tools used could be important in enhancing bio-specimen donations and subsequently improve treatments and diagnostic tools for this population.

Also, this study had some notable strengths including the culturally tailored materials and the focus of this study was primarily to educate low-income African Americans about bio-specimen donation. The limitations of this study includes, the knowledge and attitudes about bio-specimen donation were assessed in the short-term, without follow-up to determine if these improvements could lead to actual bio-specimen donation, this study included a small convenience sample, both of which may affect the generalizability of the results.

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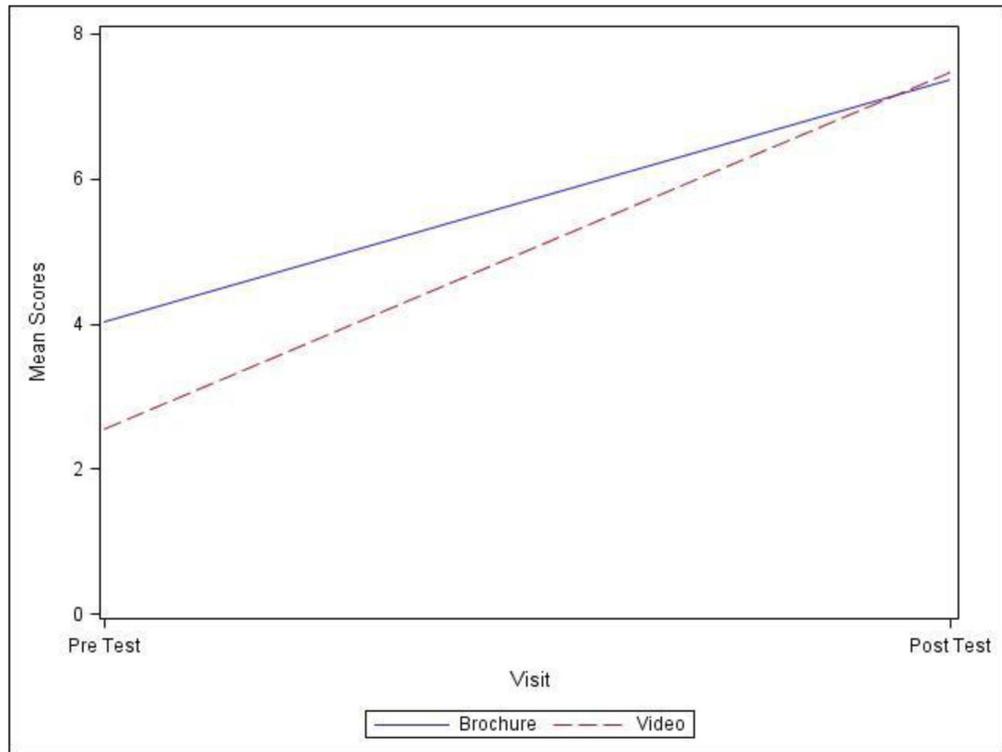


Figure 1.
Plot of Means for Knowledge Scores by Information Method

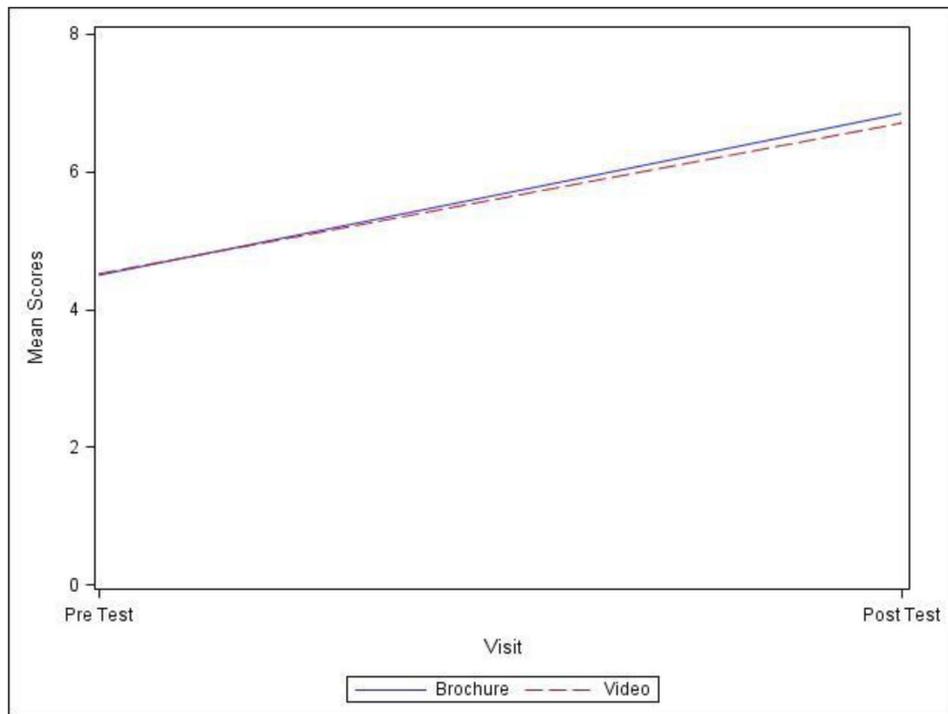


Figure 2.
Plot of Means for Attitude Scores by Information Method

Table 1

Demographic and Lifestyle Characteristics of Participants at Entry into the Study

Variables	Brochure (N = 55) [1]	Video (N = 57) [1]	P-Value [2]
Age at interview (years)	39.2 (12.17), 39.0 (29.0, 50.0)	41.8 (14.52), 41.0 (29.0, 50.0)	0.5156
Gender			
Female	27 (49.1)	29 (50.9)	0.8501
Male	28 (50.9)	28 (49.1)	
Education			
Below High School	7 (12.7)	10 (17.5)	0.8426
High School	20 (36.4)	21 (36.8)	
Some College (1 to 3 years)	18 (32.7)	12 (21.1)	
College (4 or more years)	10 (18.2)	14 (24.6)	
Marital Status			
Married/Unmarried Couple	8 (14.5)	10 (17.9)	
Divorced/Widowed/Separated	12 (21.8)	13 (23.2)	0.8555
Never Married	35 (63.6)	33 (58.9)	
Employment Status			
Employed	34 (61.8)	32 (58.2)	0.6971
Unemployed	21 (38.2)	23 (41.8)	
Annual Household Income			
< \$15,000	23 (46.0)	19 (37.3)	
\$15,000 – \$25,000	9 (18.0)	11 (21.6)	0.6697
> \$25,000	18 (36.0)	21 (41.2)	
General Health Status			
Excellent/Very Good/Good	44 (81.5)	43 (76.8)	0.5449
Fair/Poor	10 (18.5)	13 (23.2)	
Health Insurance			
Yes	40 (74.1)	41 (71.9)	0.5373
No	13 (24.1)	16 (28.1)	
Participant knows about the different types of biospecimens			
Yes	24 (43.6)	14 (24.6)	0.0330
No	31 (56.4)	43 (75.4)	
Participant understand how donating biospecimen helps toward cancer and other medical research			
Yes	36 (65.5)	26 (45.6)	0.0347
No	19 (34.5)	31 (54.4)	
Participant understand how biospecimens are stored in tissues			
Yes	20 (36.4)	12 (21.1)	0.0730
No	35 (63.6)	45 (78.9)	
Participant understand the benefits of donating biospecimens			
Yes	34 (61.8)	25 (43.9)	0.0570

Variables	Brochure (N = 55) [1]	Video (N = 57) [1]	P-Value [2]
No	21 (38.2)	32 (56.1)	
Participant understand how to donate biospecimens			
Yes	27 (49.1)	10 (17.5)	0.0004
No	28 (50.9)	47 (82.5)	
Participant understand what info researchers require along with biospecimens			
Yes	23 (41.8)	15 (26.3)	0.0832
No	32 (58.2)	42 (73.7)	
Participant understand the risk of donating biospecimens			
Yes	21 (38.2)	13 (22.8)	0.0769
No	34 (61.8)	44 (77.2)	
Participant understand how privacy is protected in donating biospecimens			
Yes	36 (65.5)	30 (52.6)	0.1679
No	19 (34.5)	27 (47.4)	
Participant has privacy concerns regarding donating biospecimens for research			
Strongly or somewhat agree/No opinion	42 (76.4)	40 (70.2)	
Somewhat disagree	3 (5.5)	6 (10.5)	0.6260
Strongly disagree	10 (18.2)	11 (19.3)	
Participant trust researchers with their biospecimens			
Strongly or somewhat agree/No opinion	24 (43.6)	30 (52.6)	
Somewhat disagree	12 (21.8)	12 (21.1)	0.2961
Strongly disagree	19 (34.5)	15 (26.3)	
Participants religious beliefs prevent them from donating their biospecimens for research			
Strongly or somewhat agree/No opinion	13 (23.6)	13 (22.8)	
Somewhat disagree	6 (10.9)	6 (10.5)	0.8984
Strongly disagree	36 (65.5)	38 (66.7)	
Participant would be likely to donate following the death of a family member due to chronic disease			
Strongly or somewhat agree/No opinion	48 (87.3)	47 (82.5)	
Somewhat disagree	5 (9.1)	5 (8.8)	0.3332
Strongly disagree	2 (3.6)	5 (8.8)	
Participant was fearful of donating biospecimens due to the consequences of doing so			
Strongly or somewhat agree/No opinion	35 (63.6)	36 (63.2)	
Somewhat disagree	10 (18.2)	8 (14.0)	0.7399
Strongly disagree	10 (18.2)	13 (22.8)	
Participants believe they can help others by donating their biospecimens			
Strongly or somewhat agree/No opinion	10 (18.2)	12 (21.1)	
Somewhat disagree	33 (60.0)	34 (59.6)	0.6542
Strongly disagree	12 (21.8)	11 (19.3)	
Participant will consider donating biospecimens in the future			
Yes	49 (92.5)	46 (80.7)	0.0727
No	4 (7.5)	11 (19.3)	

Variables	Brochure (N = 55) [1]	Video (N = 57) [1]	P-Value [2]
Participant intends to donate blood or any other biospecimens in the next 30 days			
Yes	11 (20.8)	12 (21.1)	0.9694
No	42 (79.2)	45 (78.9)	

[1] Frequency (percent) for a categorical variable, Mean (Standard Deviation), Median (First Quartile, Third Quartile) for a continuous variable.

[2] Chi-square test for a categorical variable, CMH for an ordinal variable and Wilcoxon rank-sum test for a continuous variable.

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Table 2

Pre-Post Mean Test Scores for Bio-Specimen Educational Tools

Information Method	Bio-Specimen Knowledge Scores			Bio-Specimen Attitude Scores		
	Pre Test (N = 112)	Post Test (N = 112)	P-Value [2]	Pre Test (N = 112)	Post Test (N = 112)	P-Value [2]
Brochure (N=55)	4.0±0.38	7.4±0.19	<.0001	4.5±0.36	6.8±0.42	<.0001
Video (N=57)	2.5±0.33	7.5±0.18	<.0001	4.5±0.35	6.6±0.43	<.0001
Both (N=112)	3.3±0.26	7.4±0.13	<.0001	4.5±0.25	6.7±0.30	<.0001

[1] Higher scores represent higher knowledge and more favorable attitudes towards donating bio-specimen.

[2] P-value from paired sample t-test.

[3] Main effect Knowledge score has F = 212, P-value < 0.0001, main effect method has F = 5.87, P-value = 0.0170 and the interaction has F = 7.87, P-value = 0.0061.

[4] Main effect Attitude score has F = 78.56, P-value < 0.0001, main effect method has F = 0.06, P-value = 0.8085 and the interaction has F = 0.31, P-value = 0.5817.