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Development and Validation of the Biobanking Attitudes and Knowledge Survey (BANKS)

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Abstract

Background—No validated multi-scale instruments exist that measure community members' views on biobanking and biospecimen donation. This study describes the development and psychometric properties of the English-language BANKS (**B**iobanking **A**ttitudes a**N**d **K**nowledge **S**urvey).

Methods—The BANKS was created by item generation through review of scientific literature, focus groups with community members, and input from a community advisory board. Items were refined through cognitive interviews. Content validity was assessed through an expert panel review. Psychometric properties of the BANKS were assessed in a sample of 85 community members.

Results—The final BANKS includes 3 scales: Attitudes, Knowledge, and Self-Efficacy; as well as 3 single items, which evaluated receptivity and intention to donate a biospecimen for research. Cronbach's alpha coefficients for two scales that use Likert response format indicated high internal consistency (Attitudes: α =.88; Self-Efficacy: α =.95). Content validity indices were moderate, ranging from 0.69 to 0.89. Intention to donate blood and intention to donate urine were positively correlated with attitudes, knowledge, self-efficacy, and receptivity to learning more about biobanking (*p*'s range from .029 to <.001).

Conflicts of Interest. The authors have no conflicts of interest to disclose.

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Conclusions—The final BANKS shows evidence of satisfactory reliability and validity, is easy to administer, and is a promising tool to inform biospecimen research. Additional studies should be conducted with larger samples considering biospecimen donation to further assess the instrument's reliability and validity.

Impact—A valid and reliable instrument measuring community members' views about biobanking may help researchers evaluate relevant communication interventions to enhance understanding, intention, and actual biospecimen donation. A Spanish-language BANKS is under development.

Keywords

Biobanking; tissue banking; survey; reliability; validity

INTRODUCTION

The science of oncology is undergoing a transformation, whereby biospecimen research is an increasingly important tool to develop new ways to prevent, detect, and treat cancer.[1] In order to move closer to achieving goals related to personalized medicine and individualized cancer care, participation in biobanks by large numbers of multi-ethnic individuals is essential. As biobanks are being implemented, there has been public concern about such issues as privacy, genetic discrimination from employers and insurance providers, custodianship, regulation of scientific research, and compensation or other benefit derived from donated tissues.[2-12] Attitudes regarding participation in biomedical research, participation in research in general, and participation in biospecimen donation vary by age, race and ethnicity.[13, 14] For example, middle age and older adults are more willing to donate a biospecimen or establish a biobank.[15-17] In addition, a higher percentage of people were willing to donate a biospecimen for cancer research as compared to genetic research, research on general knowledge of body tissues, or research testing medicine.[18] It is important to know what people think, believe and understand about the risks and benefits of providing samples as it is likely that they will be asked to donate at some point in a clinical healthcare encounter. As such, communications and discussions about biospecimen donation and biobanking should be detailed, open, and honest.[1, 19] The use of community engagement methods to improve communications and understanding of biospecimen donation and biobanking is one way to bring constituents' voices into discussions. Such participatory methods can influence the way biobanks are implemented since accountability, transparency, and proper monitoring are central to engender and maintain the public's trust and improve diversity. [1, 20, 21]

As biobanking is a relatively new concept, there are limitations in the research literature. Existing measures used to evaluate knowledge about and attitudes toward biospecimen donation and biobanking are often drafted at high literacy levels [16, 22-25] and have not been validated. [12, 16, 19, 22, 24-28] Also, many items used in previous studies have been single item measures of knowledge [23] or attitudes. [25, 29, 30] Currently, there are no known published multi-item scales that evaluate knowledge regarding and attitudes toward biospecimen donation and biobanking that have been validated in any populations recruited in the United States. Furthermore, there are no known validated scales evaluating self-efficacy for biospecimen donation and biobanking. Therefore, the objectives of this paper are to (1) describe the development of an instrument containing three multiple-item English-language Likert scales, respectively evaluating knowledge of, attitudes towards, and self-efficacy related to biospecimen donation; and, (2) provide preliminary evidence of psychometric properties of the scales. In addition, this paper reports the development of three single items measuring receptivity to learning more about biobanking and intention to

donate a biospecimen to a biobank. It is expected that the systematic development of such an instrument addresses a significant gap in biospecimen science. Further, it is anticipated that the instrument will have high portability to other settings for both evaluation of utility of biobanking educational materials/interventions, and assessment of biospecimen donation knowledge and attitudes among community members.

This study, fueled by our community partners' interest in the topic of biobanking, was carried out as part of a series of community-engaged biospecimen research activities of the Tampa Bay Community Cancer Network's (TBCCN; Drs. Meade and Gwede, Multiple Principal Investigators), one of 23 Community Network Program Centers nationwide funded by National Cancer Institute's (NCI's) Center to Reduce Cancer Health Disparities. As background, TBCCN is a formalized community-academic partnership comprised of 23 local community-based organizations in the Tampa Bay area and a NCI-designated comprehensive cancer center. Originally established in 2005, the goal of TBCCN is to tackle cancer health disparities among medically underserved populations within Hillsborough, Pinellas, and Pasco counties in west-central Florida.[31]

MATERIALS AND METHODS

Development of the Item Pool

This project was approved by the University of South Florida Institutional Review Board and, builds on a prior study, the *Tampa Bay Community Cancer Network (TBCCN) Community Perceptions on Biobanking Project* (3U01CA114627-05S2). [17] As part of the prior project, a Biobanking Community Advisory Board (B-CAB) was formalized and established to provide guidance on the qualitative research to explore knowledge of, and attitudes toward, biobanking among healthy community members. For this project, the B-CAB also continued to offer valuable assistance with the development and refinement of items for the instrument, Biobanking Attitudes and Knowledge Survey (BANKS).

Using the Knowledge-Attitudes-Behavior (KAB) approach, the research team generated items for each BANKS scale through a literature review of existing measures and a content analysis of the 12 focus groups conducted by the TBCCN Community Perceptions on Biobanking Project. [17] The review of the literature showed a scarcity of measures that assessed the constructs of interest and were appropriate for community populations in the United States. For instance, some items assessed attitudes towards DNA banking among health professionals [32] and cancer patients' views and perceptions about tumor donations [33], whereas other items explored attitudes and knowledge of biospecimen donation among the general public in Europe. [25, 29, 34] Focus group data [17] helped to generate an initial pool of English-language items. The items were generated to reflect the major themes and ideas that emerged from the discussions (e.g. concerns about loss of privacy and cloning, fears that insurance companies or other organizations police might access a person's donated biospecimens, concerns about pain/discomfort from donation procedures, desire for monetary compensation, desire to help friends and family affected by chronic diseases, optimism regarding the positive impact of biospecimen research on future generations, etc). In developing items and instructions for completing the BANKS, the research team took care to use clear language and terms that were easy to understand. During the initial item development phase, the B-CAB provided input in the selection of terms that were literacy and linguistically appropriate to the community. Upon the completion of several rounds of appraisals and modifications, the team prepared an advanced draft for cognitive testing with community members.

Description of the BANKS Measures

The BANKS includes three multiple-item scales and three single items. A cover sheet includes instructions for completing the BANKS with the following information about biospecimens and biobanks: "Biospecimens are materials from the body, like blood, urine, skin, or saliva that a person can donate for science. Biospecimens are collected and then stored in biobanks, which are like libraries of stored biospecimens. Scientists can use biospecimens in research to find new ways to treat diseases like cancer." The instructions were developed with the assistance of the B-CAB and were finalized based on feedback obtained during cognitive interviews.

BANKS-Attitudes—The first draft included 25 attitudes items measuring attitudes towards biospecimen donation and biobanking. Each item included either a positive or negative attitude statement which a person would rate using a five-point Likert scale ranging from "strongly agree" to "strongly disagree."

BANKS-Knowledge—The first draft included 17 knowledge items. Each item included a factual statement about biospecimen donation and biobanking. The responses on the scale included "yes," "no" and "don't know."

BANKS-Self-Efficacy—The first draft included 16 self-efficacy items. Each item queried the confidence a person has in donating a biospecimen to a biobank given different situations. The original numeric rating scale ranged from 0 to 100, with 0 indicating "Cannot Do" and 100 indicating "Highly Certain I Can Do."

BANKS-Intention and Receptivity—The research team drafted two single items to measure intention to donate blood and intention to donate urine. The team also developed a single item to assess receptivity to learning more about biospecimen donation and biobanking. All items were measured on a five point Likert scale ranging from "Definitely Yes" to "Definitely No".

Instrument Refinement

Cognitive Interviews—A trained research coordinator conducted twelve cognitive interviews with community members identified with the assistance of the B-CAB, to evaluate readability, language and wording, participant understanding, and cultural appropriateness of items and instructions. Participants included in cognitive interviews were: 1) receiving health care, educational, or social services from a TBCCN community partner organization; 2) able to speak and read English; 3) 18 years; 4) living in the Tampa Bay area of Florida; and 5) able to provide informed consent. Community members were excluded from cognitive interviews if they had previously participated in the *TBCCN Community Perceptions on Biobanking Project*.

The research coordinator conducted the interviews using a cognitive interview guide [35] developed by the research team that included probes on comprehension and interpretation of items, paraphrasing, evaluation of item difficulty, and overall understanding. Using the guide, the research coordinator asked participants to read instructions and questions and to respond to each question using the responses provided. The research coordinator observed and recorded if participants had difficulty understanding instrument instructions, understanding or interpreting survey questions, and/or providing an appropriate response to the question. After participants provided an answer to each item, the research coordinator asked questions to determine whether they understood the question and comprehended the terminology. The research coordinator conducted three interviews with different participants and then revised the item pool. This process was repeated four times resulting in a total of

12 interviews being conducted. Participants were recruited for cognitive interviews until no additional changes in the survey were being suggested. Participants were provided a \$20 incentive for participating in a cognitive interview.

Content Validity—The next step in the instrument refinement cycle was to conduct a content validity (CV) assessment with an expert panel of five investigators with knowledge and expertise on biobanking and instrument development. The panel of experts was selected from a list of investigators from the NCI-funded Geographic Management Program (GMaP) and Minority Biospecimen/Biobanking Program (BMaP) who were not part of the BANKS development team. Once identified, the experts were asked to review and rate the relevancy of items on a 4-point Likert scale (e.g., not relevant, somewhat relevant, quite relevant, very relevant). A multi-rater content validity index (CVI) was calculated using a method described by Polit & Beck [36], where an item content validity index (I-CVI) and a scale content validity index (S-CVI) were calculated in addition to the standard item-by-item agreement across experts. The I-CVI indicates the number of items that experts rated as quite relevant or very relevant, and the S-CVI indicates the number of items that were rated relevant by all experts. Experts also provided suggestions for item improvement.

Pilot Testing—Once the research team completed the iterative process of item development, cognitive interviewing, and evaluation for content validity, the refined BANKS items were pilot tested. Pilot test participants were recruited from health fairs, community events, and referrals from the B-CAB and TBCCN community partners in the Tampa Bay area of Florida. To be included in the pilot test, participants were required to be: 1) receiving health care, educational, or social services from a TBCCN partner; 2) able to speak and read English; 3) 18 years; 4) living in the Tampa Bay area of Florida; and 5) able to provide informed consent. Participants were excluded if they had participated in the prior *TBCCN Community Perceptions on Biobanking Project*.

After obtaining written consent, the research coordinator requested each participant complete the pilot test version of the BANKS, which included the cover page with instructions for completing the BANKS and definitions of biospecimen and biobanking. Research staff assisted any participants that had difficulty reading or completing surveys. In addition to completing the BANKS instruments, participants were asked to complete a brief demographic questionnaire (i.e., gender, age, race, ethnicity, marital status, education, employment, income). Participants were provided a \$10 incentive for completing the pilot test survey.

Data Management and Psychometric Analyses

All pilot test data were entered into an SPSS datafile for analysis and screened for missing data through an evaluation of frequencies and out of range values. Preliminary analyses examined the distribution of data on each scale and on each single item measure (mean, standard deviation, range, skewness). As described in the results section, there were minimal missing data. The missing data that did exist were imputed using the mean of each variable. After imputing missing data, the BANKS-Intention and BANKS-Receptivity, as well as the positively worded items on the BANKS-Attitudes scale were reverse coded so that higher scores indicated more positive responses. Items on the BANKS-Attitudes and BANKS-Self-efficacy scales were summed to indicate a total scale score. Internal consistency was evaluated for the BANKS-Attitudes and Self-efficacy scales using Cronbach's alpha and a review of item-to-total correlations for each scale. Items that were found to have poor internal consistency, indicated by an increase in Cronbach's alpha if deleted or an item-to-total correlation under .30, were deleted from the final scale. For the BANKS-Knowledge scale, items answered correctly on the BANKS-Knowledge were summed to get a total

number of correct items ("don't know" responses were coded as having answered the item incorrectly).

Construct validity was assessed by the known-groups method using several hypotheses.[37] It was anticipated that people who indicated they intended to donate blood or urine to a biobank would have: more receptivity to learning more about biospecimen donation and biobanking; more positive attitudes towards biospecimen donation and biobanking; higher self-efficacy for donating a biospecimen; and more knowledge of biospecimen donation and biobanking. In addition, it was anticipated that people with more knowledge of biospecimen donation and biobanking would have more positive attitudes and higher self-efficacy related to biospecimen donation and biobanking. All known group hypotheses were tested using Pearson correlations. A sample size of 85 participants was selected in order to be able to detect a Pearson correlation with a medium effect size (.5) at $\alpha = .05$, and with 80% power. [38] Data analyses were conducted using SPSS. Readability of the final BANKS items was assessed using the SMOG formula. [39]

RESULTS

Cognitive Interviews

Based on 12 cognitive interviews, 31 BANKS items were modified to improve readability and clarity; 15 items were deleted based on content sensitivity and item comprehension; and seven items were added (see Table 1 for examples of item edits). In addition, the range of the response scale for the BANKS-Self-Efficacy scale was changed from 0 to 100 to 0 to 10 to enhance understanding. Table 2 shows demographics of participants who participated in cognitive interviews.

Content Validity and Expert Review

The CVI values ranged from .20 to 1.0 for the BANKS-Attitudes scale (I-CVI=.69; S-CVI=. 28; 21 items); .60 to 1.0 for the BANKS-Knowledge scale (I-CVI=.78; S-CVI=.17; 17 items); and .80 to 1.0 for the BANKS-Self-efficacy scale (I-CVI=.89; S-CVI=.45;11 items). None of the items on the BANKS-Self-efficacy scale had an I-CVI less than .80, so all items on this scales were retained for pilot testing. Based on the CVI value range (.60-1.0) of the BANKS-Knowledge scale and expert feedback, one item was modified, one was deleted, and one new item was added to the scale. The BANKS-Attitudes scale had the lowest I-CVI values, indicating fewer items were rated as relevant by experts. As a result, of those items with scores of .60 or less, two were modified based on feedback received from the CV experts; eight items were deleted, and two new items were added to the scale (see Table 1 for examples of item edits provided by expert reviewers).

Pilot Testing

Following cognitive interviewing and content validity assessment, the revised BANKS scales comprised: 15 attitude items, 16 knowledge items, and 12 self-efficacy items, as well as 3 single items measuring intention to donate blood, intention to donate urine, and receptivity to learning more about biospecimen donation and biobanking.

Two-hundred seventy-five participants were approached to take part in the pilot testing of the BANKS, and 117 (42.5%) met inclusion criteria. Of those individuals, 86 (73.5%) agreed to participate with 85 (72.6%) participants completing the BANKS. Most participants were female (69.4%), African-American (59.5%), non-Hispanic (89.2%), not married or living with a partner (63.1%), and employed full-time (58.4%; Table 3). The mean age was 42.7 years (standard deviation [SD]: 16.8 years). On average, participants reported completing 11.9 years of education (SD: 0.48 years).

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There were minimal missing data (no item had more than 2.4% missing data), so no item was deleted or revised based on tendency for missing data, but was instead imputed using the mean of the item. A review of the frequency of correct responses on the BANKS-Knowledge revealed there was a range of item difficulty. The percent of correct answers provided on items ranged from 16.7% to 79.8%. On average, participants answered 6.6 out of 16 BANKS-Knowledge questions correctly (Tables 4 and 5). A review of distribution of responses on BANKS-Attitudes items revealed variation in responses. No item showed significant skewness, as indicated by a skewness value greater than 1 or less than -1. The distribution of responses on BANKS-Self-efficacy items also revealed variation in responses. One item, "I think I could give a biospecimen to a biobank even if I am not feeling well" was significantly positively skewed indicating that participants were likely to indicate they were certain they could do this. Despite the skewness of the item, it was retained in the scale.

Internal Consistency

Both the BANKS-Attitudes and BANKS-Self-efficacy scales demonstrated adequate internal consistency (Cronbach's alpha =.87 and .95, respectively). A review of item-to-total correlations for the BANKS-Attitudes indicated that one item "Giving blood to a biobank might be scary because a person would have to be stuck with a needle" had an item-to-total correlation of .26 and multiple negative correlations with other BANKS-Attitudes items. As a result, it was deleted from the final scale, which increased the scale's internal consistency slightly (Cronbach's alpha=.88). This left 14 items in the final BANKS-Attitudes scale.

Construct Validity

As anticipated, participants who indicated they were more likely to agree to donate urine or blood to a biobank had: more receptivity to learning more about biospecimen donation (r =. 41, p<.001 [urine]; r=.39, p<.001 [blood]); more positive attitudes towards biospecimen donation and biobanking (r=.41, p<.001 [urine]; r=.27, p=.01 [blood]); higher self-efficacy for donating a biospecimen (r=.51, p<.001 [urine]; r=.63, p<.001 [blood]), and more knowledge of biospecimen donation and biobanking (r=.24, p=.029 [urine]; r=.27, p=.014 [blood]). In addition, as hypothesized, people with more knowledge of biospecimen donation and biobanking (r=.36, p=.001) and higher self-efficacy related to biospecimen donation and biobanking (r=.34, p=.001).

Reading Level

The final version of the BANKS was assessed for readability. Our first estimate of readability using the SMOG formula[39] was found to be grade 11. This formula relies on polysyllabic word counts. However, two polysyllabic words, *biospecimen* and *biobanking*, were frequently used in some of the BANKS scales. As these polysyllabic terms are common terms within this health content area, it did not make sense to eliminate them in the BANKS scales. However, since we provided an explanation and definition of these terms before administrating the BANKS, we decided to recalculate the readability score by eliminating these words in the readability calculation. When we did that, the adjusted readability score of the BANKS instrument was grade 8.

DISCUSSION

To our knowledge, the BANKS instruments are the first measure of constructs related to biospecimen donation and biobanking that have been developed using an iterative community-engaged process and assessed for validity and reliability. Developed through the ongoing guidance and input of a B-CAB, and through multiple iterations with community members, the final BANKS instrument includes three scales which measure: biobanking

attitudes (14 items), biobanking knowledge (16 items), and self-efficacy for donating a biospecimen (12 items), as well as 3 single-item measures of intention to donate a biospecimen and receptivity to learning more about biospecimen donation and biobanking (total of 45 items; see Appendix for items in the order in which they were administered). These items were drafted based on focus group data [17] and a review of existing measures, and refined through the conduct of a series of iterative steps. Critical to the creation of the BANKS items was the B-CAB that provided suggestions to develop and refine items and make the items more clear, and the BANKS expert panel that assessed items for content validity. Pilot testing of the BANKS indicated that the measures were easy-to- administer and that participants could complete them with little missing data. Pilot testing also provided evidence of high internal consistency of the two Likert scale measures (BANKS-Attitudes and BANKS-Self-efficacy). In addition, our pilot work indicated the measures demonstrated evidence of construct validity. Overall, our lower literacy measures, albeit grade 11 or 8, greatly improve on previous research which utilized items written at high literacy levels [16, 22-25] or that were not validated [12, 16, 22, 24-28]. Also, the BANKS-Knowledge, BANKS-Attitudes, and BANKS-Self-efficacy scales are the first multi-item scales to assess biobanking-related knowledge, attitudes, and self-efficacy, developed through a highly participatory process with community members.

Although careful and systematic steps were taken to create the BANKS, there are some limitations to the research. First, the initial pilot testing of the BANKS was conducted in a small sample of English-speaking community members in Florida who were not being asked to donate a biospecimen for research at that time. The BANKS is currently being used to evaluate a biobanking educational intervention consisting of a video and booklet. The next steps for this line of research include the collection of additional data from a larger sample of people being asked to donate a biospecimen to further assess the reliability and validity of the measures by correlating scores with actual donation rather than intent, as well as conducting confirmatory factor analysis and Rasch analysis. In addition, while the sample was diverse, additional data need to be collected in other populations to further examine the psychometric characteristics of the BANKS. To that end, we address the limitation of the lack of biobanking-related measures in other languages, by developing a Spanish-language translation of the BANKS, which is currently being evaluated for reliability and validity.

In conclusion, the BANKS is a valid and reliable set of measures of constructs related to biospecimen donation and biobanking. Future research, conducted with a larger sample with ready access to a biobank, should further assess reliability and validity of the BANKS measures, such as through confirmatory factor analysis or Rasch analysis. Furthermore, this study contributes to the literature a valid and reliable biobanking instrument to assess community's attitudes, knowledge and self-efficacy, and advances national imperatives to encourage and expand high quality biobanking and biospecimen research for diverse populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Sample Item Wording Modifications Obtained through: Expert Reviews and Cognitive Interview Testing with Community Members

BANKS - Attitudes Scale				
Original Item	Participant Comments (Expert or Cognitive Interview)	Final Item		
1. People who give biospecimens may help prevent diseases	Remove 'may'' (Expert)	1. People who give biospecimens help prevent diseases		
2. Giving a biospecimen may be a waste of a person's time	Remove 'may' (Expert)	2. Giving a biospecimen is a waste of a person's time		
3. Giving a biospecimen will get in the way of a person's medical care	Remove 'will' (Expert)	3. Giving a biospecimen gets in the way of a person's medical care		
4. Personal information is likely to be stolen from a biobank	Change to positive attitude (Expert)	4. Personal information is <u>unlikely</u> to be stolen from a biobank		
BANKS - Knowledge Scale				
Original Item		Final item		
1. The results of research done with the biospecimens a person gives will show up in his/ her medical records.	"It's too wordy" (Cognitive Interview)	1. Research results from biospecimens <u>will</u> show up in medical records		
2. A researcher will call a person if his/her biospecimens show risk for a disease	"replace 'call' with 'contact'" (Cognitive Interview)	2. Researchers will always contact people if their biospecimens show risk for a disease		
BANKS - Self-efficacy Scale				
Original Item		Final item		
1. I think I could give a biospecimen even if it hurts a bit	"How painful is 'a bit'? remove 'a bit'" (Cognitive Interview)	1. I think I could give a biospecimen even if it hurts		
2. I think I could give a biospecimen to a biobank even if I feel ill	"sick? ill? How ill do I need to be not to be able to donate?" (Cognitive Interview)	2. I think I could give a biospecimen to a biobank even if I am not feeling well		

Demographic Characteristics of Cognitive Interview Participants (n=12)

Characteristic	Ν	%
Gender		
Female	5	41.7
Male	7	58.3
Race		
African American or Black	5	41.7
White	3	25.0
Multiple races	1	8.3
Other	3	25.0
Ethnicity		
Hispanic	5	41.7
Not Hispanic	7	58.3
Marital Status		
Currently married	3	25.0
Single	6	50.0
Widowed	1	8.3
Divorced	2	16.7
Employment		
Full-time (32 or more hours per week)	2	16.7
Part-time (31 or fewer hours per week)	1	8.3
Retired	1	8.3
Self Employed	4	33.3
Homemaker	1	8.3
Unemployed	3	25.0
Annual Household Income		
Less than \$10,000	2	16.7
\$10,000-\$19,999	0	0
\$20,000-\$39,999	2	16.7
\$40,000-\$59,999	1	8.3
\$60,000-\$100,000	1	8.3
Unknown	6	50.0
Education		
Less than High School	2	16.7
High School	1	8.3
Some college or vocational school	2	16.7

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Characteristic	Ν	%
College graduate	7	58.3

Demographic Characteristics of Pilot Test Participants (n=85)

Characteristic	Ν	%
Gender (n=85)		
Female	59	69.4
Male	26	30.6
Race (n=84)		
African American or Black	50	59.5
White	24	28.6
Multiple races	3	3.6
Other	7	8.3
Ethnicity (n=83)		
Hispanic	9	10.8
Not Hispanic	74	89.2
Marital Status (n=84)		
Currently married	24	28.6
Living with a partner	7	8.3
Never married	38	45.2
Divorced	15	17.9
Employment (n=84)		
Full-time (32 or more hours per week)	46	54.8
Part-time (31 or fewer hours per week)	8	9.5
Retired	16	19.0
Student	11	13.1
Disabled	2	2.4
Self-employed	1	1.2
Annual Household Income (n=70)		
Less than \$10,000	16	20.0
\$10,000-\$19,999	9	11.3
\$20,000-\$39,999	26	32.5
\$40,000-\$59,999	10	12.5
\$60,000-\$100,000	7	8.8
Greater than \$100,000	2	2.5
Education (n=83)		
Less than 8 th grade	2	2.4
Less than High School	8	9.4
High School	35	41.2
Some college or vocational school	24	28.2
College graduate	10	11.8

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Characteristic	N	%
Graduate School	4	4.7

Scale and Item Means, Standard Deviations, and Inter-item Correlation.

Item	Mean	Standard Deviation	Item to Total Correlation
BANKS Attitudes Scale (Total score range: 38-70)	52.47	7.79	
1. Giving a biospecimen is for the greater good of society	4.01	0.87	0.53
2. People who give biospecimens help prevent diseases	4.05	0.82	0.67
3. People who give biospecimens help cure diseases	4.05	0.74	0.60
4. Giving a biospecimen is a waste of a person's time	3.93	0.96	0.70
5. Giving a biospecimen will help future generations	4.22	0.70	0.69
6.Giving a biospecimen gets in the way of a person's medical care	3.68	1.05	0.55
7. Giving a biospecimen will help a person's family	4.0	0.79	0.63
8. Medical information is unlikely to be stolen from a biobank	3.31	1.02	0.38
9. Giving blood to a biobank is a good way to help cancer research	4.21	0.74	0.66
10. Personal information is unlikely to be stolen from a biobank	3.25	1.03	0.33
11. Giving blood to a biobank might be scary because a person would have to be stuck with a needle $**$	2.89	1.15	0.26
12. A person's family medical information is safe in a biobank	3.48	0.89	0.42
13. Biospecimens that people donate might be used for purposes they do not want	3.23	0.97	0.43
14. A person should not donate biospecimens because it might identify health problems	3.54	1.15	0.48
15. Giving biospecimens to a biobank may lead to more health care costs	3.52	1.05	0.44
BANKS Knowledge Scale (range: 0-15)	6.64	4.25	
BANKS Self-efficacy Scale (Total score range: 0-120)	47.95	32.67	
1. I think I could give a biospecimen to a biobank even if I have not donated a biospecimen before	5.54	3.41	0.65
2. I think I could give a biospecimen to a biobank even if I had to travel far to do so	3.48	3.30	0.62
3. I think I could give a biospecimen to a biobank even if it hurts	4.02	3.15	0.81
4. I think I could give blood to a biobank even if I feel weak	3.02	3.27	0.70
5. I think I could give a biospecimen to a biobank even if my family does not want me to	5.08	3.43	0.81
6. I think I could give a biospecimen to a biobank even if it is against my cultural beliefs	3.79	3.72	0.85
7. I think I could give blood to a biobank even if it hurts	4.08	3.56	0.89
8. I think I could give a biospecimen to a biobank even if I am worried about how it will be used	3.94	3.08	0.85
9. I think I could give a biospecimen even if I am not feeling well	2.25	2.69	0.65
10. I think I could give a biospecimen to a biobank even if I am afraid of needles	4.46	3.47	0.87
11. I think I could give a biospecimen to a biobank even if it is against my religious beliefs	3.66	3.87	0.81
12. I think I could give a biospecimen to a biobank even if I have to spend more time at a doctor's office.	4.62	3.24	0.74
BANKS Intention			
If you were asked to give a urine sample for research, would you agree to do it? (range: 2-5)	4.13	0.91	

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Item	Mean	Standard Deviation	Item to Total Correlation
If you were asked to give a blood sample for research, would you agree to do it? (range 1-5)	3.86	1.18	
BANKS Receptivity (range: 2-5)			
If you were asked to give a biospecimen for research, would you be willing to hear more information about it?	4.02	0.89	

** Item was removed from final version of the scale

Numbers and Percentages of People Who Endorsed Each Response on Knowledge Items.

BANKS Knowledge Scale	Yes N (%)	No N (%)	Don't Know N (%)
1. A person has to spend money to give a biospecimen	4 (4.8)	41(48.8)	39 (46.4)
2. Anyone can access the biospecimens a person gets	4 (4.8)	37(44.6)	42(50.6)
3. Research results from biospecimens will show up in medical records	10(12.0)	24(28.9)	49(59.0)
4. Biospecimens given to a biobank will be sold to drug companies	6(7.1)	40(47.6)	38(45.2)
5. A scientist mut keep a person's information private when doing research	67(79.8)	9(10.7)	8(9.5)
6. The biospecimens people give can be sent to any organization that requests them	10(11.9)	35(41.7)	39(46.4)
7. Police departments can legally give the biospecimens a person gives	8(9.5)	31(36.9)	45(53.6)
8. Biospecimens given to a biobank can be sold to anyone.	4(4.8)	49(58.3)	31(36.9)
9. Insurance companies can legally get the biospecimens a person gives.	2(2.4)	40(47.6)	42(50.0)
10. Researchers will always contact people if their biospecimens show risk for disease.	35(41.7)	14(16.7)	35(41.7)
11. A person's family can get information about the biospecimens a person gives.	10(11.9)	37(44.0)	37(44.0)
12. People can make money from donated biospecimens.	18(21.2)	25(29.4)	42(49.4)
13. People no longer own their biospecimens after they give them to a biobank.	20(23.5)	14(16.5)	51(60.0)
14. After a person gives a biospecimen to a biobank, she/he can get it back.	4(4.7)	36(42.4)	45(52.9)
15. A person might be cloned if he/she donates a biospecimen to a biobank.	5(6.0)	41(48.8)	38(45.2)
16. A person can stop being in a research study after giving a biospecimen.	34(40.0)	10(11.8)	41(48.2)