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Development and Validation of the Biomedical Research Trust Scale (BRTS) in English and Spanish

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Abstract

This study developed and validated the Biomedical Research Trust Scale (BRTS), a 10-item measure of global trust in biomedical research, in English and Spanish (BRTS-SP). In total, 85 English- and 85 Spanish-speaking participants completed the BRTS or BRTS-SP, as well as measures of biobanking attitudes, self-efficacy, receptivity, and intentions to donate blood or urine. Results indicated the BRTS and BRTS-SP showed adequate internal consistency in both English and Spanish. In addition, greater levels of trust in biomedical research were significantly associated with greater self-efficacy, receptivity, attitudes, and intentions to donate blood and urine in English-speaking participants, and self-efficacy and intention to donate urine in Spanish-speaking participants. These results support the use of the BRTS and BRTS-SP among English- and Spanish-speaking community members.

Keywords

biomedical research; biobanking; biospecimen donation; trust; survey; questionnaire; reliability; validity

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Biomedical research includes basic research, applied research, and translational research to study the biological processes and genetic and environmental factors related to human health

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and disease, and to develop new approaches to prevention, screening, diagnosis, and treatment of specific diseases or health conditions (Biomedical Research, 2006; California Biomedical Research Association, n.d.). In clinical trial research, individuals are asked to participate in studies to determine whether a particular medical device (e.g., stent), procedure (e.g., surgery), or treatment (e.g., drug) is efficacious and safe (Chang et al., 2002). In biospecimen research, individuals are asked to participate by donating a biospecimen to a biobank for research (Centers for Disease Control and Prevention, National Office of Public Health Genomics, 2007; Hewitt, 2011; Organisation for Economic Co-Operation and Development, 2006; Streicher et al., 2011; Vaught et al., 2011).

Numerous studies examining patients’ and community members’ perceptions of clinical trials and biospecimen research have suggested that trust is an important factor in willingness to participate in biomedical research. For example, trust in medical researchers (e.g., Armstrong, Crum, Rieger, Bennett, & Edwards, 1999; Bussey-Jones et al., 2010; Crawley, 2001; Earl & Penney, 2001; Ellington, Wahab, Sahami Martin, Field, & Mooney, 2006; Hodge, Weinmann, & Roubideaux, 2000; LaVeist, Nickerson, & Bowie, 2000; Roberson, 1994; Shavers, Lynch, & Burmeister, 2001; Skinner et al., 2008), health care providers (e.g., Durant, Legedza, Marcantonio, Freeman, & Landon, 2011; Haynes-Maslow et al., 2014; Jenkins & Fallowfield, 2000; Nurgat et al., 2005; Rahm, Wrenn, Carroll, & Feigelson, 2013; Volkmann, Claiborne, & Currier, 2009), health care system (e.g., Areán & Gallagher-Thompson, 1996; Gamble, 1993; Giuliano et al., 2000; LaVeist et al., 2000; McCabe, Varricchio, & Padberg, 1994; Shavers et al., 2001), and research institutions (e.g., Critchley, Nicol, Otlowski, & Stranger, 2012; Lemke, Wolf, Hebert-Beirne, & Smith, 2010; Skolbekken, Ursin, Solberg, Christensen, & Ytterhus, 2005) has been associated with intentions to participate in a clinical trial or a biobank. However, research on trust related to biomedical research participation has been hampered by the lack of validated, multi-item measurement tools, as most studies used single-item or unvalidated, multi-item measures of trust (Bussey-Jones et al., 2010; Critchley et al., 2012; Kettis-Lindblad, Ring, Viberth, & Hansson, 2006; Lemke et al., 2010; Ormond, Smith, & Wolf, 2010; Platt, Bollinger, Dvoskin, Kardia, & Kaufman, 2013; Rahm et al., 2013; Skinner et al., 2008). In addition, previous studies evaluating trust in biomedical research have primarily assessed trust in a specific profession or entity (e.g., researchers, academic institutions), without accounting for the wide range of stakeholders involved in biomedical research.

While there are validated measures that assess trust in medical researchers (Hall et al., 2006; Mainous, Smith, Geesey, & Tilley, 2006), physicians (Anderson & Dedrick, 1990; Corbie-Smith, Thomas, & George, 2002; Hall, Camacho, Dugan, & Balkrishnan, 2002; Leisen & Hyman, 2001; Safran et al., 1998), health insurers (Zheng, Hall, Dugan, Kidd, & Levine, 2002), or the health care system (Rose, Peters, Shea, & Armstrong, 2004; Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004), these measures are specific to a single profession or entity. There is currently no validated measure that evaluates trust in multiple stakeholders (individual or institution) that community members may associate with biomedical research. In practice, the biomedical research enterprise is comprised of many different stakeholders, with different individuals and institutions conducting, regulating, and using research. Qualitative studies indicate that community members have trust concerns regarding the stakeholders directly involved in regulating and using stored biospecimens in research (e.g., Beskow & Dean, 2008; Godard, Marshall, & Laberge, 2007; Gustafsson Stolt, Liss, Svensson, & Ludvigsson, 2002; Haddow, Cunningham-Burley, Bruce, & Parry, 2008; Kaphingst, Janoff, Harris, & Emmons, 2006; Kaufman et al., 2008; Levitt & Weldon, 2005; Luque et al., 2012; McCarty, Chapman-Stone, Derfus, Giampietro, & Fost, 2008; Ormond, Cirino, Helenowski, Chisholm, & Wolf, 2009; Secko, Preto, Niemeyer, & Burgess, 2009), as well as individuals and institutions that may not directly be related to biomedical research. For example, concerns about the police or government having unauthorized access to donated biospecimens are barriers to participating in a biobank (e.g., Halverson & Ross, 2012; Lemke, Halverson, & Ross, 2012; Lewis et al., 2013; Luque et al., 2012), although law enforcement has no direct involvement in biomedical research. Thus, broad-based assessment of biomedical research trust, consisting of various individuals and institutions that community members associate with biomedical research, is needed to further understand community members' trust in biomedical research.

The present study describes the development and preliminary assessment of psychometric properties of a 10-item measure of global trust in biomedical research (Biomedical Research Trust Scale; BRTS) in English and Spanish (BRTS-SP) languages. Unlike previous trust measures that were specific to a particular profession or institution, the BRTS aims to measure community members' trust in biomedical research in general by assessing trust in various stakeholders associated with biomedical research.

Materials and Method

Overview of the Development of the BRTS

The BRTS and BRTS-SP were developed as part of a series of projects conducted by the Tampa Bay Community Cancer Network (TBCCN) related to biospecimen donation and biobanking (U54 CA153509; Arevalo et al., 2015; Luque et al., 2012; Wells et al., 2014). TBCCN is a community-academic partnership that aims to reduce cancer disparities by conducting evidence-based research projects guided by community-based participatory research (CBPR) principles, health promotion outreach, and capacity-building and training activities in a tri-county area of Tampa Bay, Florida (Simmons et al., 2015).

The research team developed the BRTS and BRTS-SP as broad, multi-item measures of trust in biomedical research based on the following conceptualization of trust: community members' reliance on individuals and institutions involved in or associated with biomedical research. In this conceptualization, trust implies a feeling of security in spite of lack of control over the actions of these stakeholders, even though negative consequences from biomedical research are possible. The BRTS assesses an individual's degree of trust in professionals, organizations, and facilities that may or may not be related to biomedical research (e.g., medical scientists, doctors, universities, government agencies, hospitals, police), but which community members associate with biomedical research. The BRTS was developed in two phases. In Phase 1, the English version was developed and its psychometric properties were evaluated. In Phase 2, the Spanish version was developed and its psychometric properties were evaluated. The BRTS was developed and tested along with the English-language Biobanking Attitudes and Knowledge Survey (BANKS; Wells et al., 2014). The BRTS-SP was developed and tested along with the Spanish-language Biobanking

Attitudes and Knowledge Survey (BANKS-SP; Arevalo et al., in press). The BANKS and BANKS-SP instruments include three multi-item scales evaluating attitudes toward, knowledge of, and self-efficacy related to biospecimen donation and biobanking, as well as three single items evaluating intention to donate a biospecimen and receptivity toward learning more about biospecimen donation and biobanking. A Biobanking Community Advisory Board (B-CAB) provided guidance on the development, refinement of items, interpretation of results, and dissemination efforts for the BRTS, BANKS, BRTS-SP, and BANKS-SP (Arevalo et al., in press; Wells et al., 2014).

In Phase 1, the BRTS was refined through cognitive interviews and expert review, and then piloted tested in an English-speaking community sample, along with the BANKS measures. In Phase 2, the final versions of the BRTS and the BANKS measures were translated from English- to Spanish-language using the Brislin Model of Translation (Brislin, 1970; Jones, Lee, Phillips, Zhang, & Jaceldo, 2001). Along with the BANKS-SP, the BRTS-SP was evaluated and refined via cognitive interviewing with Spanish-speaking participants. The final Spanish version of the BRTS was then pilot tested along with the Spanish version of the BANKS in a Spanish-speaking community sample. This study protocol was reviewed and approved by the University of South Florida Institutional Review Board. All study participants provided written informed consent.

Phase 1: Development and Validation of the English-Language BRTS

Development of the BRTS items—The research team generated items for both versions of the BRTS through a literature review of previous studies with measures of trust related to biomedical research and a content analysis of 12 focus groups (nine conducted in English; three conducted in Spanish; Luque et al., 2012). These focus groups identified distrust in researchers as an emerging theme in community members' perceptions of biospecimen research and identified various individuals and organizations that community members associated with biomedical research (Luque et al., 2012).

Refinement of the BRTS item pool—Once the research team created a list of potential items for the BRTS, these items were compiled in a survey format along with instructions for completion of the BRTS. The first BRTS draft included 15 items evaluating trust or distrust in various individuals and institutions that may or may not be related to research (e.g., researchers/scientists, hospitals, police). The initial scale responses ranged from 0 (*I do not trust*) to 100 (*I completely trust*). The first set of items and instructions was reviewed by research team members and the B-CAB, which included two Spanish-English bilingual and bicultural members. Items and instructions continued to be refined based on expert review.

Cognitive interviews—The BRTS was evaluated and refined through 12 cognitive interviews with 12 English-speaking community members from Tampa Bay, Florida, along with items from the BANKS measures, which were simultaneously being developed (Wells et al., 2014). Cognitive interview participants were (a) able to speak and read English; (b) receiving health care, educational, or social services from a TBCCN community partner organization; (c) 18 years and older; (d) living in the Tampa Bay area of Florida; and (e) able to provide informed consent. A trained research coordinator used a cognitive interview guide that was developed by the research team to evaluate participants' comprehension and interpretation of survey items and instructions, as well as readability, language, and wording. After revisions were made as a result of cognitive interviews, the refined BRTS included 10 items measuring trust in individuals and organizations that community members associated with biomedical research. Each item was rated for degree of trust using a 10-point scale, with 0 indicating *do not trust*, 5 indicating *moderately trust*, and 10 indicating *completely trust*.

Pilot testing—Upon completing the iterative process of item development and refinement through cognitive interviews and expert review, the refined 10-item BRTS was piloted tested, along with the refined BANKS items, in a community sample of 85 English-speaking participants. Participant recruitment was conducted at community events, health fairs, and through referrals from the B-CAB and TBCCN community partners in Tampa Bay, Florida. To be eligible for inclusion in the pilot test, participants were required to be (a) able to speak and read English; (b) receiving health care, educational, or social services from a TBCCN partner; (c) 18 years or older; (d) living in the Tampa Bay area of Florida; and (e) able to provide informed consent. Previous participants from the focus group study (Luque et al., 2012) were excluded from participation.

After obtaining written consent, each participant completed the pilot test version of the BRTS along with a brief demographic questionnaire and the BANKS. Research staff provided assistance if participants reported difficulty reading or completing surveys. Participants were provided US$10 for completing the pilot test surveys. In addition to the BRTS, the following self-report measures were included in the pilot testing of the instrument:

Demographics—Demographic questions assessed age, marital status, gender, race, ethnicity, income, education, and employment.

BANKS-Attitudes—The BANKS-Attitudes scale evaluates participants' attitudes toward biospecimen donation and biobanking (Arevalo et al., in press; Wells et al., 2014). The English version contains 15 attitude items (Wells et al., 2014), while the Spanish version contains 12 items (BANKS-SP-Attitudes; Arevalo et al., in press), of either a positive or negative statement. Items are scored on a 5-point Likert-type scale ranging from 1 = *strongly disagree* to 5 = *strongly agree*. BANKS-Attitudes scores are calculated by first reverse coding negatively worded items and then summing across all scale items. The BANKS-Attitudes scale has adequate internal consistency in English ($\alpha = .88$; Wells et al., 2014) and Spanish ($\alpha = .77$; Arevalo et al., in press).

BANKS-Knowledge—The BANKS-Knowledge scale assesses participants' knowledge regarding biospecimen donation and biobanking, and includes 16 factual statements in which participants respond *yes*, *no*, or *don't know* (Arevalo et al., in press; Wells et al., 2014). BANKS-Knowledge scores range from 0 to 16, and represent the total number of items answered correctly.

BANKS-Self-Efficacy—The BANKS-Self-Efficacy includes 12 items that assess participants' confidence in different situations to donate a biospecimen to a biobank (Arevalo et al., 2015; Wells et al., 2014). Response options range from 0 to 10 (0 = *I cannot do*; 5 = *moderately certain I can do*; 10 = *highly certain I can do*). Summed scores are computed with higher scores indicating greater self-efficacy. The BANKS-Self-Efficacy demonstrated strong internal consistency in English ($\alpha = .95$; Wells et al., 2014) and Spanish ($\alpha = .91$; Arevalo et al., in press).

BANKS-Intention and BANKS-Receptivity—Two single items measure intention to donate blood and intention to donate urine to a biobank for research (BANKS-SP-Intention: Arevalo et al., in press; BANKS-Intention: Wells et al., 2014). One single item measures participants' receptivity toward learning more about biospecimen donation and biobanking (BANKS-SP-Receptivity: Arevalo et al., in press; BANKS-Receptivity: Wells et al., 2014). All single items are rated on a 5-point Likert-type scale ranging from 1 = *definitely no* to 5 = *definitely yes*. Scores are reverse coded so that higher scores indicate greater intention or greater receptivity.

Data analysis of the BRTS pilot test data—Preliminary analyses examined the distribution of data on each BRTS item (means, standard deviation, range, and skewness). Internal consistency of the BRTS was evaluated using Cronbach's alpha. Item-to-total correlations were also evaluated to identify and remove any items with negative or weak correlations with the total scale. Items with 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. All items on the BRTS were summed for a possible range between 0 and 100, and then construct validity of the BRTS was assessed by the known-groups method using several hypotheses (DeVellis, 2003). It was hypothesized that people who reported greater levels of trust in biomedical research would have more positive attitudes toward biospecimen donation and biobanking; higher self-efficacy in donating a biospecimen; greater receptivity to learning more about biospecimen donation and biobanking; and would be more likely to donate blood or urine to a biobank. All known group hypotheses were tested using Pearson correlations. A sample size of 85 participants was selected to be able to detect a Pearson correlation with 80% power and a medium effect size (0.5) at $\alpha = .05$ (Cohen, 1988). SPSS version 22.0 was used to analyze data (IBM Corp, 2013).

Phase 2: Development and Validation of the Spanish-Language BRTS (BRTS-SP)

Spanish translation of the BRTS—As described by Arevalo and colleagues (Arevalo et al., in press), the final version of the BRTS (10 items), along with the BANKS, was translated from English to Spanish (BRTS-SP; BANKS-SP) using a consensus model of translation based on the recommendations of Brislin (1970; Jones et al., 2001).

Instrument refinement of the BRTS-SP

Cognitive interviews: A trained bilingual (fluent in English and Spanish) research coordinator conducted 10 cognitive interviews with 10 Spanish-speaking community members in Tampa Bay, Florida, to evaluate the Spanish translation of the BRTS-SP along with the BANKS-SP (Arevalo et al., in press). Interviews were conducted using a cognitive interview guide that was developed by the research team to evaluate the cultural appropriateness, language and wording, readability, and participant interpretation and comprehension of the survey instructions and items in Spanish. Cognitive interview participants were (a) able to speak and read Spanish; (b) receiving health care, educational, or social services from a TBCCN community partner organization; (c) 18 years and older; (d) living in the Tampa Bay area of Florida; and (e) able to provide informed consent.

Pilot testing: The BRTS-SP was pilot tested with the BANKS-SP in a community sample of Spanish-speaking adults from Tampa Bay, Florida (Arevalo et al., in press). Participants were recruited from community events, health fairs, and through referrals from community partners of TBCCN. To be eligible for inclusion in the pilot test, participants were required to be (a) able to speak and read Spanish; (b) receiving health care, educational, or social services from a TBCCN partner; (c) 18 years and older; (d) living in the Tampa Bay area of Florida; and (e) able to provide informed consent. Those who participated in the prior focus group project (Luque et al., 2012) or cognitive interviews were excluded. After providing written consent, participants were requested to complete the pilot test versions of the BRTS-SP and the BANKS-SP, as well as a brief demographic questionnaire (see Phase 1 for descriptions of the BANKS-SP and demographic variables). Participants were provided US $10 for completing the pilot test surveys.

Data analysis of the BRTS-SP pilot test data: Analysis of pilot test data for the BRTS-SP was conducted using the same method used in Phase 1 of the study for the English BRTS.

Results

Phase 1: BRTS

Cognitive interviews—A total of 12 cognitive interviews were conducted with English-speaking participants using the BRTS and BANKS (see Table 1). Based on English cognitive interviews, the BRTS was refined to a total of 10 items, and the range of the response scale was simplified from 0 to 100 to 0 to 10.

Pilot testing—In all, 276 participants were approached to take part in the pilot testing of the BRTS. Of the 117 individuals who met inclusion criteria, 86 (73.5%) agreed to participate with 85 (72.6%) participants completing both the BANKS and BRTS questionnaires (Table 2). Most participants were female (69.4%), African American (59.5%), employed (65.5%), and received at least some high school education (51.8%). The average age of pilot test participants was 42.7 years (*SD* = 16.8 years).

There were no missing data on the BRTS. A review of the distribution of responses on BRTS items revealed variation in responses, but there were no significantly skewed items on the BRTS, as indicated by a greater than 1 or less than −1 skewness value.

Internal consistency—The BRTS demonstrated good internal consistency in English (α = .92). Item-to-total correlations ranged from .44 to .82 (see Table 3).

Construct validity—As anticipated, English-speaking participants who indicated greater levels of trust in biomedical research had more positive attitudes toward biospecimen donation and biobanking ($r = .59$, $p < .001$), higher self-efficacy related to biospecimen donation ($r = .68$, $p < .001$), more receptivity to learning more about biospecimen donation ($r = .32$, $p = .003$), and were more willing to donate blood ($r = .37$, $p = .001$) and urine ($r = .44$, $p < .001$; Table 4). Based on evaluation of descriptive data, internal consistency, and assessment of construct validity, no BRTS item was deleted or revised from the English version of the scale.

Phase 2: BRTS-SP

Cognitive interviews—A total of 10 cognitive interviews were conducted with 10 Spanish-language-preferring participants to evaluate the Spanish translation of the BRTS-SP (see Table 1 for cognitive interview participant demographic characteristics). Based on Spanish cognitive interviews, one item was modified to improve clarity.

Pilot testing—As described elsewhere (Arevalo et al., in press), 101 participants were approached to take part in the pilot testing of the BRTS-SP. In all, 85 (84.2%) participants met inclusion criteria and completed the BRTS-SP. Most participants self-identified as Hispanic (96.5%) and were female (70.6%), White (62.4%), married (56.5%), employed (71.4%), and had some level of higher education (69.6%). The mean age was 46.3 years (*SD* = 13.4 years; Table 2).

There were minimal missing data on the BRTS-SP (no item had more than 2% missing data). The distribution of responses on the BRTS-SP items also indicated variation in responses, but no item showed significant skewness.

Internal consistency—The BRTS-SP demonstrated good internal consistency ($\alpha = .93$). Item-to-total correlations ranged from .65 to .79 (see Table 3).

Construct validity—Correlations between the BRTS-SP and BANKS-SP are detailed in Table 4. As anticipated, Spanish-speaking participants who indicated greater levels of trust had higher self-efficacy related to biospecimen donation ($r = .54$, $p < .001$) and were more willing to donate blood ($r = .23$, $p = .04$). However, trust was not statistically significantly correlated with attitudes toward biospecimen donation and biobanking ($r = .21$, $p = .06$), intention to donate urine ($r = .21$, $p = .06$), or receptivity to learning more about biobanking ($r = .13$, $p = .24$).

Discussion

The BRTS and BRTS-SP are the first validated, multi-item measures of global trust in the biomedical research enterprise, comprised of professionals, organizations, and facilities that are associated with biomedical research by community members. Developed using an iterative community-participatory research process and expert guidance and input from the multicultural TBCCN B-CAB, the final BRTS and BRTS-SP consist of 10 items assessing trust in various individuals and institutions that community members associate with biomedical research. The BRTS and BRTS-SP underwent several revisions during expert review and cognitive interviewing, which resulted in a brief assessment tool that is easy to complete, as reflected by the lack of missing data in pilot testing. The items were initially drafted in English, based on focus group data collected from both English and Spanish speakers (Luque et al., 2012), as well as a review of existing measures and previous studies evaluating trust related to biomedical research participation, then refined through a series of iterative steps, and pilot tested with English-speaking community members. The final BRTS items were translated into Spanish using a rigorous process. The BRTS-SP was refined via cognitive interviews and pilot tested with Spanish-speaking community members.

Pilot testing indicated response variation in the items, with no item significantly skewed, and provided evidence of high internal consistency in both languages. Pilot testing of the BRTS also demonstrated evidence of construct validity with the English BANKS scales and most of the Spanish BANKS scales. Biomedical research trust was significantly associated with attitudes toward biospecimen donation and biobanking, self-efficacy related to biospecimen donation, receptivity to learning more about biospecimen donation, and intentions to donate blood and urine in the English-speaking participants. For the Spanish-speaking participants, trust was not statistically significantly associated with measures of attitudes, receptivity, or intention to donate urine; however, the associations between biomedical research trust and these variables were all in the expected direction (positively correlated). Also, the correlations between biomedical research trust and biobanking attitudes, as well as intention to donate urine, approached statistical significance ($p = .06$). Because correlations were in the expected direction, no items were removed from the BRTS-SP. The lack of statistically significant correlations shows a similar pattern to the BANKS-SP scales. Unlike the English BANKS, some of the Spanish BANKS scales were not statistically significantly associated with one another as hypothesized, specifically, knowledge of biospecimen donation and biobanking was not statistically associated with measures of intention to donate a biospecimen, receptivity to learning more about biospecimen donation and biobanking, attitudes toward biospecimen donation and biobanking, and self-efficacy for a donating biospecimen (Arevalo et al., in press). The weaker correlational results for the BRTS-SP compared with the English version may reflect lack of power to detect a smaller effect (small sample size); demographic differences between the two pilot test samples, as nearly 90% of the Spanish-speaking participants were born outside of the United States; differences in awareness or familiarity with biomedical research; or true group differences in factors associated with biomedical research trust among English- and Spanish-speaking community members. Additional research should be conducted with a larger Spanish-speaking sample to further evaluate the psychometric properties of the BRTS-SP and BANKS-SP scales.

There are several limitations to this study. First, the present evaluation of the psychometric properties of the BRTS and BRTS-SP is limited by the small sample sizes used to conduct the pilot tests. Also, recruitment of participants was conducted exclusively in Tampa Bay, Florida, with most participants being female. To substantiate the generalizability of the present findings, the psychometric properties of the BRTS will need to be examined in larger and more diverse samples. In addition, the BRTS-SP should be tested in other Spanish-speaking populations across the United States to evaluate its use in other Hispanic heritage groups. Second, the preliminary validity of the BRTS and BRTS-SP is limited to the context of biospecimen research, as it was assessed with measures of constructs specific to biospecimen donation and biobanking. The BRTS and BRTS-SP should be examined in the context of clinical trial participation to further evaluate the scale's validity and utility as a general trust measure of biomedical research. Third, the pilot tests assessed community members' willingness to donate a biospecimen for research, and did not ask participants to donate a biospecimen at that time. Future research should examine the BRTS and predictors related to actual donation of a biospecimen or participation in a clinical trial, rather than intentions to donate or participate. Despite these limitations, the study provides preliminary evidence of the reliability and validity of the BRTS and BRTS-SP, as brief, multi-item biomedical research trust measures, among English- and Spanish-speaking community members.

Best Practices

The BRTS and BRTS-SP are brief multi-item scales measuring trust in biomedical research. As a global trust measure, the BRTS measures community members' trust in biomedical research in general by assessing the various stakeholders associated with biomedical research, rather than one specific professional or institutional role. This more broad-based assessment of biomedical research trust distinguishes the BRTS from previous trust measures. This study provides evidence of reliability and validity for the BRTS and BRTS-SP among English- and Spanish-speaking community members. Results from this study also demonstrated that community members' trust in biomedical research was significantly associated with intention to donate a biospecimen for research, and indicated that greater levels of trust may increase self-efficacy in donating a biospecimen and positive attitudes toward biobanking and biospecimen donation. These findings underscore the role of trust in community members' perceptions about and decisions to participate in biomedical research, and, thus, the importance of measuring and evaluating biomedical research trust. This 10-item measure of global trust in biomedical research is recommended for future use in research or clinical settings with English- and Spanish-speaking community members.

Research Agenda

A valid and reliable measure of biomedical research trust has significant potential to advance biomedical research in several ways. First, the BRTS and BRTS-SP can be used to evaluate whether there are certain populations who lack biomedical research trust. Biomedical researchers can then better engage these populations and communities in the research enterprise. Second, future studies can empirically evaluate the predictive utility of trust in biomedical research for future willingness and participation in a clinical trial or biobank study, as well as explore the relationships between biomedical research trust and other factors associated with research participation, such as knowledge, attitudes, self-efficacy, and receptivity. Third, these tools can help the field understand what predicts and alters trust in biomedical research. This understanding may lead to the development of better communication interventions to explain biomedical research to potential research participants, improve community members' trust in biomedical research, and increase participation in biomedical research. Finally, these tools can help evaluate communication or other types of interventions that focus on improving perceptions or understanding of biomedical research.

Educational Implications

Although researchers have identified biomedical research as integral to advancing progress in health and medicine, there remains a gap between community members and researchers regarding biomedical research. Previous research has indicated trust is a significant factor in research participation. In particular, trust emerged via formative research as a concern in community members and stakeholders who may be considering participation in biomedical research (Luque et al., 2012). Consequently, we developed the first validated, multi-item measure of global trust in English- and Spanish-speaking community members. Results from this study emphasize the role of trust in community members' willingness to participate in biomedical research, and thus the importance of educating researchers and other research stakeholders regarding the trust concerns some populations express. By understanding these trust concerns, stakeholders may be able to better address these issues and have more opportunities for more open dialogue about the trust concerns these various communities may have. In addition, having a fuller understanding of potential participants' trust concerns may help inform the development of interventions to build trust between various stakeholders in the biomedical research enterprise.

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Sharon H. Baik, MS, is a doctoral student in the San Diego State University/University of California, San Diego Joint Doctoral Program in Clinical Psychology, specializing in Behavioral Medicine. Her research interests include studying the biopsychosocial factors involved in the etiology, detection, treatment, and survivorship of cancer, as well as health disparities among underserved populations, and access to health care and health information. Ms. Baik analyzed the pilot test data, contributed significantly to the interpretation of the study results, and drafted the manuscript.

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Table 1

Demographic Characteristics of Cognitive Interview Participants.

	English (*N* = 12)		**Spanish (*N* = 10)**	
Characteristic	***N***	**%**	***N***	**%**
Gender				
Female	5	41.7	10	100
Male	7	58.3	0	0
Race				
African American or Black	5	41.7	0	0
White	3	25.0	6	60.0
Multiple races	1	8.3	2	20.0
Other	3	25.0	2	20.0
Ethnicity				
Hispanic	5	41.7	10	100
Not Hispanic	7	58.3	0	0
Marital status				
Currently married	3	25.0	4	40.0
Single	6	50.0	3	30.0
Widowed	1	8.3	0	0
Divorced	2	16.7	3	30.0
Employment				
Full-time (32 or more hours per week)	2	16.7	3	30.0
Part-time (31 or fewer hours per week)	1	8.3	4	40.0
Retired	1	8.3	0	0
Self-employed	4	33.3	0	0
Homemaker	1	8.3	3	30.0
Unemployed	3	25.0	0	0
Annual household income				
Less than US$10,000	2	16.7	3	30.0
US$10,000-US$19,999	0	0	0	0
US$20,000-US$39,999	2	16.7	5	50.0
US$40,000-US$59,999	1	8.3	0	0
US$60,000-US$100,000	1	8.3	0	0
Unknown	6	50.0	2	20.0
Education				
Less than high school	2	16.7	3	30.0
High school	1	8.3	2	20.0
College or vocational school	9	75.0	4	40.0
Graduate degree	0	0	1	10.0

Table 2

Demographic Characteristics of Pilot Test Participants.

	English (*N* = 85)		**Spanish (*N* = 85)**	
Characteristic	***N***	**%**	***N***	**%**
Gender	(*n* = 85)		(*n* = 85)	
Female	59	69.4	60	70.6
Male	26	30.6	25	29.4
Race	(*n* = 84)		(*n* = 80)	
African American or Black	50	59.5	4	4.7
White	24	28.6	53	62.4
Multiple races	3	3.6	9	10.6
Other	7	8.3	14	16.5
Ethnicity	(*n* = 83)		(*n* = 84)	
Hispanic	9	10.8	82	96.5
Not Hispanic	74	89.2	2	2.4
Marital Status	(*n* = 84)		(*n* = 85)	
Currently married	24	28.6	48	56.5
Never married	45	53.6	22	25.9
Divorced	15	17.9	15	17.6
Employment	(*n* = 84)		(*n* = 84)	
Full-time (32 or more hours per week)	46	54.8	38	44.7
Part-time (31 or fewer hours per week)	8	9.5	6	7.1
Retired	16	19.0	7	8.2
Student	11	13.1	13	15.3
Disabled	2	2.4	4	4.7
Self-employed	1	12	16	18.8
Annual household income	(*n* = 70)		(*n* = 83)	
Less than US$10,000	16	20.0	15	17.6
US$10,000-US$19,999	9	11.3	16	18.8
US$20,000 to US$39,999	26	32.5	30	35.3
US$40,000 to US$59,999	10	12.5	8	9.4
US$60,000 to US$100,000	7	8.8	6	7.1
Greater than US$100,000	2	2.5	1	1.2
Education	(*n* = 83)		(*n* = 79)	
Less than eighth grade	2	2.4	11	13.9
High school or high school graduate	43	51.8	13	16.5
Some college or vocational/technical school	24	28.2	37	46.8
College graduate	10	11.8	14	17.7
Graduate or professional degree	4	4.7	4	5.1

Table 3

Scale and Item Means, Standard Deviations, and Inter-Item Correlations of the Biomedical Research Trust Scale.

	English (*N* = 85)			Spanish (*N* = 85)		
Item	***M***	***SD***	**Item to total correlation**	***M***	***SD***	**Item to total correlation**
Biomedical Research Trust Scale	5.47	2.09		5.99	2.09	
1. Medical scientists	6.05	2.86	.73	6.53	2.37	.65
2. Hospitals	6.55	2.75	.80	6.65	2.55	.68
3. Medical laboratories	6.28	2.71	.80	6.86	2.44	.75
4. Health insurance companies	4.47	2.58	.51	4.19	2.78	.67
5. Universities or colleges that do medical research	5.95	2.90	.64	6.73	2.61	.68
6. Doctors that do medical research	6.52	2.83	.77	6.68	2.47	.79
7. Drug/pharmaceutical companies	4.86	2.83	.67	5.07	2.74	.75
8. Government agencies that do medical research	4.15	2.73	.75	5.74	3.04	.78
9. Clinics	5.47	2.52	.82	6.22	2.68	.78
10. Police	4.42	2.97	.44	5.17	3.09	.70

Table 4

Correlations Between the Biomedical Research Trust Scale and the BANKS Scales and Items.

	English language (*N* = 85)		**Spanish language (*N* = 85)**	
	Biomedical Research Trust Scale			
BANKS scale and items	***R***	***p***	***r***	***p***
Attitudes	.585	<.001	.208	.062
Self-Efficacy	.680	<.001	.536	<.001
Receptivity	.324	.003	.133	.236
Intention to donate urine	.437	<.001	.208	.063
Intention to donate blood	.368	.001	.226	.043

Note. BANKS = Biobanking Attitudes and Knowledge Survey; *r* = Pearson correlation.