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A Community-Based Approach to Biospecimen Collection Among Pacific Islanders

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This study tested the feasibility of collecting saliva samples from Pacific Islanders (PIs) via a community-based participatory research approach. Collection of saliva samples were conducted by trained and trusted PI community leaders at various partner sites. A total of 214 saliva samples were donated by PIs living in Southern California, more than half of whom were females between the ages of 18 and 35 years. Donors indicated that they donated because they wanted to help science and their community. A majority of donors reported a very positive experience with the donation process and were willing to donate saliva and hair samples in the future. The positive findings of this article highlight the importance of community input and participation.

Keywords: *Pacific Islanders; biospecimen; saliva; collection; donation*

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► BACKGROUND

The National Cancer Institute (NCI) defines biospecimens as biological samples taken from humans, such as hair, nail, urine, saliva, or blood (NCI, 2014). Scientists have been studying biospecimen samples as part of cancer research for many decades, and in fact, the demand for such samples in cancer research has grown by 400% in the past 20 years (Hughes, Barnes, & Watson, 2010). Despite the increased need for biospecimen samples, the majority of samples have come from non-Hispanic White donors, and the pool of diverse samples from racial/ethnic minorities has been limited (James, Yu, Henrikson, Bowen, & Fullerton, 2008; Thompson & Hébert, 2014).

Advancements in personalized medicine and the need to ensure generalizability of study results underline the importance of using biospecimen samples from diverse populations (Dang et al., 2014). Without diverse biospecimen samples and the ability to study an array of genetic makeups, researchers may not be able to effectively address the physiological and health needs of specific populations. Nevertheless, minority samples are disproportionately underrepresented in biospecimen research due to low donation rates (Dash et al., 2014; Loffredo et al., 2013; Simon et al., 2014). Studies on minority groups have documented that these low rates may be due to lack of knowledge about the benefits of biospecimen research and its implications for disease prevention (Dang et al., 2014; Kwan et al., 2015), concerns about exploitation and monetary compensation (Erwin et al., 2013; Rodriguez et al., 2016), and trust of researchers and concerns about ethical conduct (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999). Secondary data analysis of a large national representative sample revealed that there were significant differences in knowledge and concerns about genetic testing across different minority groups (Suther & Kiros, 2009). The biggest predictor of willingness to donate biospecimen samples among African Americans was concern about the transparency of the research and biobanking (Hagiwara et al., 2014). Health care attitudes and trust were significantly associated with willingness to donate biospecimen samples among Chinese Americans (Gao, Ma, Tan, Fang, Weaver, Jin, & Lai, 2014).

Increasing biospecimen sample donations from minorities involves the use of tailored materials, addressing concerns of trust and adoption of less stringent research protocols (James et al., 2008), while fostering respectful partnerships with communities and greater understanding of the informed consent process (Haring, Henry, Hudson, Rodriguez, & Taulii, 2018). Utilization of community-based outreach efforts and

approaches like community-based participatory research (CBPR) have been successful in increasing willingness to donate samples among Chinese Americans (Tong et al., 2014) and other Asian Americans (Ma, Seals, Tan, Lee, & Toubbeh, 2014). Working with trusted community partners and making community-based connections have resulted in successful blood collection for research among African Americans, Native Americans, and Hispanics/Latinos (Frye et al., 2014; Kiviniemi et al., 2013).

► PACIFIC ISLANDERS

To demonstrate how research among minorities has been translated to practice, the current article reports on the collection efforts and donors' experience with the donation of saliva samples among Pacific Islanders (PIs)—individuals of Polynesian, Melanesian, and Micronesian descent. Although PIs make up less than 1% of the total U.S. population, they disproportionately suffer from high rates of chronic diseases like cancer (Kwan et al., 2014; U.S. Census Bureau, 2012). Data from the North American Association of Central Cancer Registries showed that among Asian Americans and PIs overall cancer incidence rates are highest among Samoans and Native Hawaiians (Torre et al., 2016). Data from NCI's Surveillance, Epidemiology, and End Results registries revealed that PIs, particularly Samoans, had significantly poorer cancer survival rates than non-Hispanic Whites (Goggins & Wong, 2007). These rates are particularly alarming among a population with already high rates of health risk behaviors like smoking and alcohol consumption (Subica, Agarwal, Sullivan, & Link, 2017).

Like other minority groups, PIs are underrepresented in biospecimen research. Although previous studies have suggested some genetic predispositions for cancer among PIs (Chlebowski et al., 2005; Henderson et al., 2007; Kolonel, Altshuler, & Henderson, 2004), many do not participate in research studies, thus underscoring the need for more research involving this population. Using culturally tailored education materials and trusted PI community-based staff, the study presented in this article demonstrates the feasibility of saliva collection among PIs living in Southern California. The Pacific Islander Biospecimen Education and Collection (PIBEC) Project was conducted by the NIH/NCI-funded Weaving an Islander Network for Cancer Awareness Research and Training (WINCART) Center. Approved by the institutional review boards at both California State University Fullerton and Claremont Graduate University, the goal of the PIBEC Project was to (1) educate the PI community about the

importance of biospecimen research and (2) test the feasibility of collecting saliva samples from PIs through a CBPR approach.

A previous WINCART pilot project conducted in 2011-2012 designed to assess knowledge, attitudes, and beliefs about biospecimen research among PIs found that they supported research and were willing to donate their samples (Kwan et al., 2014). The study participants suggested that more education and outreach about the importance of biospecimen research are needed to increase participation and donation rates in their community. In response to these findings, WINCART developed several culturally tailored biospecimen education materials, outreached to a sample of PIs, and solicited voluntary saliva donations. This article describes the saliva collection activities of the PIBEC Project and reports on the experiences of donors.

► METHODS

Guided by CBPR principles, whereby community-based organizations and academic institutions take active and equal roles in the research process, the community-academic PIBEC team created three different educational materials, developed recruitment and study protocols, trained community-based staff, provided biospecimen education, conducted saliva sample collection within the communities, and assisted with interpretation of results.

Biospecimen Education Materials

An 8-minute health education video, a trifold educational brochure and an FAQ sheet guided by the Health Belief Model (Hochbaum, Rosenstock, & Kegels, 1952) were developed with the goal of educating PIs about biospecimen research and clarifying myths about biospecimen collection and storage. These materials defined biospecimens, how they may be used to identify the cause of and cure for a disease, how important such findings can be for the PI community, why PI biospecimen samples are needed, and how PIs can help by providing biospecimen samples. The video also answered questions, such as what happens to a sample after it is collected, the kinds of research the samples might be used for, and who has a say in what or how the samples will be used. A portion of the questions addressed in these materials were based on findings of the WINCART Center's earlier pilot project (Kwan et al., 2014; Kwan et al., 2015). Through CBPR, community and academic partners worked together to revise and refine multiple drafts of the materials, including making edits to the content, flow of information, and

overall graphics. Cultural tailoring of the materials included having a PI voiceover for the video, embedding PI-style graphics in the materials, plus using images of PIs as appropriate. Discussion groups made up of representative samples of the PI community were also used to obtain further input on the materials. Specific details regarding the materials and related results of the biospecimen education intervention are presented elsewhere (Tan et al., 2018). In summary, findings showed an increase in knowledge and willingness to donate after viewing the materials.

Recruitment and Study Design

PIs were recruited to participate in the PIBEC Project via recruitment practices employed by similar community-based work (Yancey, Ortega, & Kumanyika, 2006). These practices included word-of-mouth recruitment through formal and informal networks, contacting participants who were already attending workshops provided by community partners or recruiting at PI festivals, health fairs, and/or church events. Eligible participants were males and females over the age of 18 years, who self-identified as PI and were able to speak and understand English since all study-related materials were in English only.

Data Collection Flow

All data collection took place at community-based venues and was conducted by trained PI staff. Before viewing the educational materials, participants completed an online consent form detailing information about the study and a short pretest questionnaire. After viewing the materials, participants were asked if they wanted to donate their saliva sample. Staff answered any questions about the donation and assured participants that their saliva donation was strictly voluntary. Participants were told that they would receive a \$20 compensation for their input on the educational materials whether or not they donated their saliva. Participants who declined to provide a saliva sample were asked to complete a posttest questionnaire (i.e., Form A), which included a question about why they chose not to donate. Participants who agreed to donate their saliva sample completed an additional paper consent form and received more information about their donation before their saliva sample was collected. The additional information addressed the storage, banking, and use of the saliva samples. These donors then completed a different version of the posttest questionnaire (i.e., Form B), which included questions about their donation experience and why they chose to donate (see Figure 1).

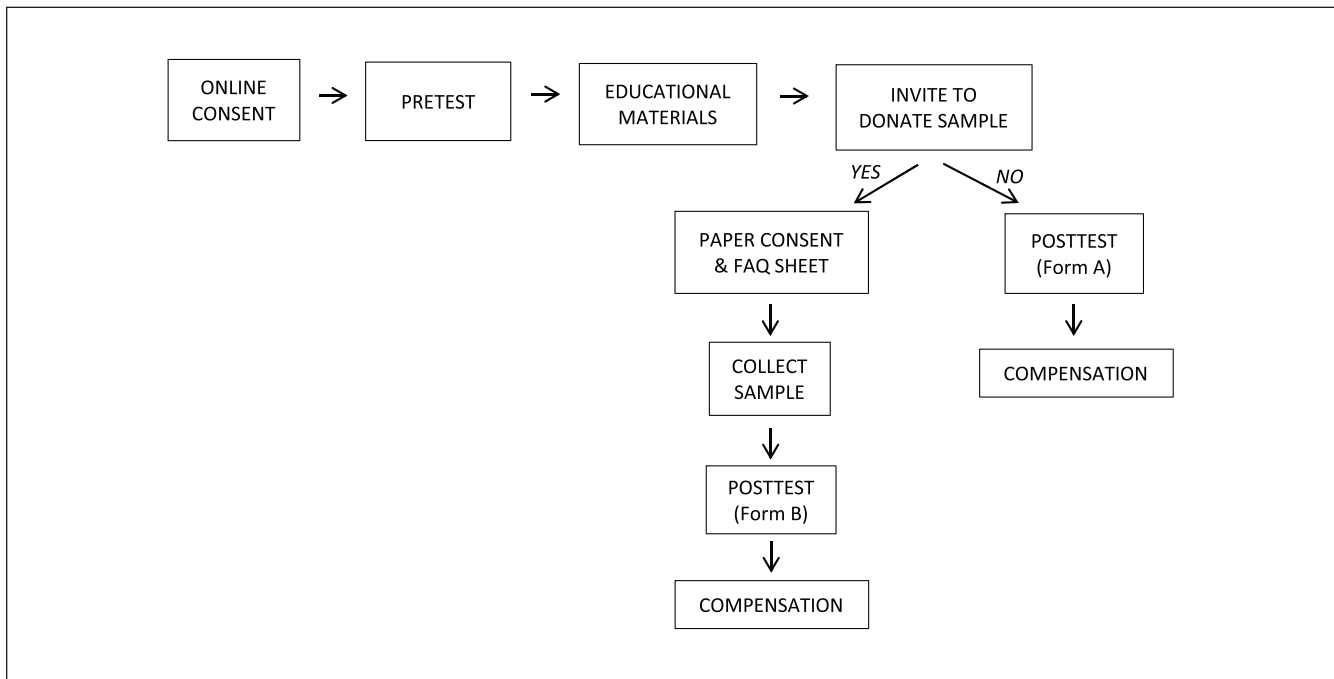


FIGURE 1 Data Collection Flow Chart

Questionnaires and Measures

A total of three short questionnaires were used for this study: (1) pretest for all participants, (2) a posttest for participants who declined to donate their saliva sample (Form A), and (3) a posttest for participants who donated their saliva sample (Form B). All questionnaires were conducted online and accessible from a computer or smartphone via a private link set up specifically for the study. Pretest measures included basic demographic questions plus biospecimen knowledge and attitude questions (e.g., degree of agreement with the statement “Donating my biospecimen sample is important because it helps scientists learn more about diseases that can affect me and my community.”). The posttest for participants who agreed to donate saliva included questions about their overall satisfaction with the experience plus a question about their reason(s) for donating with response choices, such as “Have a family history of cancer,” “Want to help science and my community,” and “Was asked by someone to donate.” Posttest measures for participants who declined to donate their saliva sample included a question asking why they did not want to donate with response options, such as “I didn’t get enough information so I don’t want to donate at this time,” “God or my beliefs makes me a little uneasy about donating,” and “I’m scared that people will take my sample and use it in the wrong way.”

Participants were told that they could mark all answer options that applied to them.

Consent Forms

Participants completed either one or two consent forms depending on whether or not they agreed to donate their saliva sample. Every participant completed an online consent form prior to taking the pretest. Those who agreed to donate their saliva sample completed an additional paper consent form, which carefully outlined information about the saliva collection protocol, storage of the sample, and how the samples might be used in future research. This second consent form was provided in a paper format because we wanted to carefully review each section of the form with the donors, making sure that they fully understood every section. Since previous studies have documented the sensitivity of biospecimen collection and storage among minority groups (Erwin et al., 2013), the PIBEC team took great care in developing consent forms that were culturally sensitive, easy to understand, and addressed the concerns of PI donors. An advisory committee consisting of researchers with expertise in biospecimen collection from the University of Washington’s Fred Hutchinson Cancer Center, the University of California Davis’s Asian American Network for Cancer Awareness, Research and Training

Center, and the University of Hawaii's 'Imi Hale Center, each representing a portion of NCI's GMaP Region 4 (now Region 5), carefully reviewed the consent forms and made suggestions for improvements. Through discussion with the advisory group, the consent form was revised to address concerns such as where the samples would be stored, who would have access to the samples, and who would have oversight of the samples and make decisions about how they would be used in the future. The second consent form also included a section to inform participants that they could request their sample be discarded at any time as well as a section asking participants whether or not they would agree to be contacted about future research with their sample.

Saliva Collection

The PIBEC Project utilized the Oragene Discover (OGR-500) saliva collection kit, which has the ability to store the collected sample at room temperature for up to 5 years. Donors can directly spit their saliva into the collection tube and seal it with a cap without any contact from the data collectors. Multiple practice sessions were carried out to train data collectors on the study protocol and collection process. During these practice sessions, community leaders demonstrated the saliva donation process with the kit and shared their feelings about the experience, many of whom reported that it was easy. To minimize contamination and mistakes, individual collection kits were created for each participant, including computer-printed labels and codes. Gloves and a biohazard bag were included in all data collection kits.

Data Analysis

All questionnaires were completed online via a private link accessible only by the data collectors and participants. Data were automatically downloaded at the conclusion of the study, cleaned, and recoded for usage. Data analysis presented in this article were analyzed via the statistical programs SAS v9.3 and STATA 14.

► RESULTS

A total of 219 people participated in the PIBEC Project. A majority of these participants were females (63.9%, $n = 140$) between the ages of 18 and 35 years (53.4%, $n = 117$). Samoans, Tongans, and Hawaiian/Native Hawaiians made up the majority of the participants (56.6%, 22.4%, and 10%, respectively). More than half of the sample had completed high school,

trade school, or college, with more than 75% having some form of health insurance. See Table 1.

We measured attitudes toward biospecimen research with the extent of agreement to the following statement, "Donating my biospecimen sample is important because it helps scientists learn more about diseases that can affect me and my community." At pretest, 16.4% ($n = 36$) of the participants said they strongly disagree with the statement, while 52.1% ($n = 114$) said that they strongly agreed. When asked the same question at posttest, the percentage of people who said they strongly disagreed with the statement dropped to 8.3% ($n = 18$), while those who strongly agreed rose to 69.9% ($n = 151$). Three people did not respond to this question at posttest.

Saliva Donation

Out of 219 participants, a total of 214 participants donated their saliva sample. A majority of the donors were female (64.5%, $n = 138$) and between the ages of 18 and 35 years (53.7%, $n = 115$). Because of the small sample size of nondonors, Fisher's exact test was conducted to look at the differences between donors ($n = 214$) and nondonors ($n = 5$). Results of the test showed no statistically significant differences between the two groups in terms of gender, age, education, PI ethnicity, or insurance coverage (Table 1). Those who did not donate their saliva sample were asked the question, "Please tell us why you did not want to donate your saliva sample today." One nondonor responded with "It's private and I don't want to provide my sample or information to others," while all others selected "I just didn't want to. There are no particular reasons."

Reasons for Donation

Table 2 reports on the reasons for donation and the types of biospecimen samples people were willing to donate. When donors were asked, "Why did you donate your saliva sample today? (mark all that apply)," 71.5% ($n = 153$) said that they wanted to help science, 41.4% ($n = 88$) reported that they donated because they have a family history of cancer, 30.4% ($n = 65$) said that they donated because someone asked them to, 26.2% ($n = 56$) said that seeing the education materials was a reason why they donated, and 23.4% ($n = 50$) said they donated because they have friends with cancer. We also asked what type of biospecimen samples they were willing to donate if asked in a future study with a "mark all that apply" option; 91.1% ($n = 195$) said that they would be willing to donate saliva, 90.7% ($n = 194$) said that they would donate hair, 48.6% ($n = 104$) said

TABLE 1
Demographic Characteristics^a

<i>Characteristic</i>	<i>All participants (n = 219)</i> <i>Frequency (%)</i>	<i>Donors only (n = 214)</i> <i>Frequency (%)</i>	<i>Fisher's Exact Test,</i> <i>Donors (n = 214) vs.</i> <i>Nondonors (n = 5)</i>
Gender			
Male	79 (36.1)	76 (35.5)	.354
Female	140 (63.9)	138 (64.5)	
Age, years			
18-35	117 (53.4)	115 (53.7)	.464
36-55	62 (28.3)	61 (28.5)	
>55	38 (17.4)	36 (16.8)	
Ethnicity ^a			
Samoan	124 (56.6)	121 (56.5)	.885
Tongan	49 (22.4)	47 (22.0)	
Hawaiian/Native Hawaiian	22 (10.0)	22 (10.3)	
Mixed NHPI	12 (5.4)	12 (5.6)	
Chamorro	10 (4.6)	10 (4.7)	
Other	2 (0.9)	2 (0.9)	
Education			
High school or less	69 (31.5)	68 (31.8)	.690
2-year college, some college, or trade school	106 (48.4)	102 (47.7)	
4-year college (bachelor's degree)	30 (13.7)	30 (14.0)	
Graduate or professional degree	14 (6.4)	13 (6.1)	
Health insurance coverage			
Yes	165 (75.3)	162 (75.7)	.192
No	39 (17.8)	38 (17.8)	
Not sure	12 (5.5)	11 (5.1)	

NOTE: NHPI = Native Hawaiian Pacific Highlander.

^aBecause of the small sample size of nondonors ($n = 5$) and in an effort to preserve participants' confidentiality, demographic data for this group are not being presented in this table.

TABLE 2
Donor Response to Donation Questions ($n = 214$)

<i>Donor Response to Questions</i>	<i>Frequency (%)</i>
Reasons for Donation (Mark All Apply)	
Want to help science and my community	153 (71.5)
Have a family history of cancer	88 (41.1)
Was asked by someone to donate	65 (30.4)
Seeing the educational materials	56 (26.2)
Have friends with cancer	50 (23.4)
Types of biospecimen sample willing to donate in future (mark all apply)	
Saliva	195 (91.1)
Hair	194 (90.7)
Blood	104 (48.6)
Urine	97 (45.3)
Toenails	60 (28.0)

that they would donate blood, 45.3% ($n = 97$) said that they would donate urine, and 28% ($n = 60$) said that they would donate their toenails.

We also wanted to know what donors thought about the donation experience and how we could improve the process for future collection activities. The donors were asked to rate their experience on factors such as quality of the environment, smoothness of the donation process, length of time of the donation process, and knowledge of staff or research team member. More than half of the responses were either "very positive" or "positive." "Very negative" or "negative" made up less than 3% of the responses. See Table 3.

In addition to the donor's overall experience, participants were asked, "Would you recommend to a friend or family member that they donate their saliva sample in the future?" A total of 203 donors (94.9%) said yes, while 9 donors (4.2%) said that they did not know.

TABLE 3
Donation Experience (n = 214)

<i>Factor</i>	<i>Very Negative, Frequency (%)</i>	<i>Negative, Frequency (%)</i>	<i>Neutral, Frequency (%)</i>	<i>Positive, Frequency (%)</i>	<i>Very Positive, Frequency (%)</i>
Quality of the environment	0 (0)	2 (0.9)	12 (5.6)	48 (22.4)	148 (69.2)
Smoothness of the donation process	1 (0.5)	1 (0.5)	14 (6.5)	48 (22.4)	145 (67.8)
Length of time of the donation process	1 (0.5)	4 (1.9)	17 (7.9)	42 (19.6)	145 (67.8)
Knowledge of staff or research team member	2 (0.9)	2 (0.9)	11 (5.1)	29 (13.6)	166 (77.6)
Comfort with saliva donation procedure	1 (0.5)	3 (1.4)	17 (7.9)	48 (22.4)	141 (65.9)
Privacy	1 (0.5)	5 (2.3)	16 (7.5)	45 (21.0)	142 (66.4)
Trust in the staff or research team	0 (0.0)	3 (1.4)	10 (4.7)	25 (11.7)	170 (79.4)

► CONCLUSIONS

This study demonstrated the feasibility and success of saliva collection from PIs via the CBPR approach. Through joint efforts between community and academic researchers, a total of 219 PIs were educated about biospecimen research and 214 PIs voluntarily donated their saliva sample for the purposes of research and helping their community. An overwhelming majority of the saliva donors reported an overall positive experience with the donation process and would recommend a family member or friend to do the same. In line with CBPR, the PIBEC Project actively engaged community leaders representing diverse PI groups at every step of the developmental and research process. Community leaders provided guidance on the wording used in the materials and the importance of emphasizing that a donation was strictly voluntary and without compensation. Consent forms addressed PIs' concerns around harm, biospecimen storage, use, and exploitation. Educational materials emphasized the importance of PI samples for research to help their communities. Saliva collection was conducted by trained data collectors from the PI community.

The successes of the PIBEC Project mirrors that of other biospecimen collection efforts conducted among minority populations. Like the Hoy y Mañana program, which collected blood donations from Hispanic men and women, PIBEC used culturally and linguistically appropriate materials to conduct outreach and education (Rodriguez et al., 2016). Providing accurate information, leading to more informed decision making, also increased donation rates in a CBPR-guided study among African Americans and Native Americans (Kiviniemi

et al., 2013). Use of community-based organizations with well-established trust as research partners also proved successful in collecting blood donations for research among Chinese Americans (Gao, Ma, Tan, Fang, Weaver, Jin, Lai, et al., 2014).

Limitations


PIBEC has some limitations that should be noted. First, the sample of PIs who participated in this study were recruited via a nonrandom sample and thus may not represent the general PI population living in Southern California or other regions in the United States. Second, the educational materials were reviewed by PI discussion groups but were not previously tested for effectiveness and offered in English only. Last, because of the small sample size of nondonors ($n = 5$), we were not able to identify predictors of saliva donation, which would have added additional clarity to our work.

Implications

The success of this study completed through combined efforts of community and academic partners is consistent with previous studies conducted among other minority groups. Outreach to minority populations through education can reduce negative attitudes toward biospecimen research and, therefore, encourage donations of diverse samples (Kiviniemi et al., 2013). Results of this study underline the importance of (1) engaging community leaders as equal partners in the study process, (2) using tailored study materials to address the concerns of minorities and increase relevancy, and (3) involving PIs in the data collection

efforts to improve trust and ease potential discomfort. To improve donation rates among minority populations, future biospecimen collection efforts should engage the community and utilize community-friendly protocols. Without support and participation from diverse communities, the fight to reduce gaps in health disparities is difficult if not impossible. Public health professionals and biomedical researchers, who are well informed about the need to use community-friendly approaches, stand to be successful with future studies involving minority populations.

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