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Enhancing Biospecimen Knowledge among Healthcare Providers and Representatives from Community Organizations

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Abstract

In a personalized medicine environment, it is necessary to have access to a range of biospecimens to establish optimal plans for disease diagnosis and treatment for individual patients. Cancer research is especially dependent on biospecimens for determining ideal personalized treatment for patients. Unfortunately, the vast majority of biospecimens are collected from non-Hispanic white (NHW) individuals; thus, minority representation is lacking. This has negative implications for comprehensive cancer treatment. GMaP Region 6 implemented a series of biospecimen education seminars adapted from the Biospecimen and Biobanking module of an existing Cancer Education and Training Program. Regional GMaP partners participated in a train-the-trainer webinar to familiarize themselves with the training materials. Participants trained by the trainers completed pre- and post-tests to document changes in awareness, knowledge, and intention. Nine biospecimen education seminars were offered in 2013; 255 healthcare professionals and representatives from community organizations attended. Participants demonstrated a significant increase in knowledge, intention to donate samples, and intention to talk to patients about biospecimen sample donation. Representatives from community organizations had more improvement on knowledge scores than health care providers. Participation in a well-designed biospecimen education program may ameliorate some of the distrust of biomedical research experienced by racial/ethnic minorities and, in turn, increase needed minority representation in biospecimen collection.

Keywords

Biospecimen Education; Health Disparities; Cancer Education; Diversity; Minority Research Participation

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DISCLOSURE

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Introduction

Cancer research and treatment is increasingly dependent on biospecimens for determining optimal personalized treatment for cancer patients; research on biospecimens can help determine a patient's prognosis, select appropriate treatments, or measure responses to treatment.(John et al., 2004; Moore et al., 2009; J. B. Vaught, 2006) The availability of a diverse and representative supply of high-quality biospecimens is essential to ongoing cancer research. Unfortunately, the vast majority of biospecimens are collected from non-Hispanic white (NHW) individuals; representation of minority, ethnically diverse, and underrepresented groups in biospecimens is lacking, making it difficult to understand biological differences in cancers.

Background

To better understand, address, and make personalized medicine relevant to diverse groups, engaging underrepresented individuals in research participation that involves biospecimen donation is critical.(Albain, Unger, Crowley, Coltman, & Hershman, 2009) Research with biospecimens allows researchers to examine the genetic basis of a disease as well as the response to treatment. Such research can help determine a patient's prognosis, select appropriate treatments, and measure responses to treatment.(Moore et al., 2009) Without representation from people other than non-Hispanic whites, it is difficult to develop state-of-the-art treatment for the underrepresented.

Barriers to such participation in research are complex and range from social reasons such as the mistrust of many racial and ethnic groups due to historical and programmatic mistreatment in medicine (e.g., Tuskegee, Henrietta Lacks) to a cultural fear of donating samples (e.g., Chomorro, Native Americans, African Americans in the United States) to lack of awareness or access to information about the need to donate samples.(G. Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; G. Corbie-Smith et al., 2007; Durant et al., 2007; Hagiwara et al., 2014; R. V. Katz et al., 2007; Jimmie B Vaught, Lockhart, Thiel, & Schneider, 2007) In recent years, the efforts to gather biospecimens from underrepresented populations has focused on the importance of working with such communities to promote awareness of the need for biospecimens.(Dang et al., 2014; Erwin et al., 2012; Hohl, Gonzalez, Carosso, Ibarra, & Thompson, 2014; Kiviniemi et al., 2012) Subsequently, much recent research has underscored the value of community engaged approaches in increasing the number of biospecimens from underrepresented groups.(Erwin et al., 2012; Hohl et al., 2014; Kiviniemi et al., 2012; O'Doherty, Hawkins, & Burgess, 2012)

Although working with communities is a necessary part of increasing biospecimen donation, it is not sufficient to the end goal of biospecimen collection. A system must be established to encourage health care providers and their ancillary staff, as well as community organizations' representatives, to talk to individuals about the need for biospecimen donation and to offer opportunities to do so. Establishing partnerships between academia, healthcare systems, and credible community organizations presents opportunities to train stakeholders about biospecimen donation. Mobilizing community organizations to raise awareness about biospecimen donation in underrepresented communities, and partnering with facilities that

collect biospecimens can potentially increase the diversity of samples in biorepositories that are available to investigate the biological basis of cancer.

In basic cancer research, the lack of standardized, high-quality human biospecimens has been viewed as a roadblock to the rapid development of molecular diagnostics and therapeutics. Consequently, significant efforts in the National Cancer Institute (NCI) have focused on the retooling of processes and methods in national biorepositories that house human biospecimens for cancer research.(Moore et al., 2009) Although these efforts have focused on the technical aspects of biospecimen collection, much less attention has been paid to the limited representation of ethnic minority samples in existing biorepositories. As a result the NCI's efforts to gain high-quality biospecimens for cancer research is more likely to benefit NHW populations because biospecimens from this group are more readily obtained; as a result, cancer health disparities may increase. In the same way that an ethnically diverse cohort is necessary to apply the results of cancer clinical trials to the entire U.S. population (Fayter, McDaid, & Eastwood, 2007), the availability of ethnically diverse biospecimens is necessary to ensure that the molecular diagnostics and therapeutics that are developed are useful to all members of our diverse society. To meet this need all regions of the Geographic Management of Cancer Health Disparities Program (GMaP) were charged with prioritizing collection of biospecimens for cancer research from populations underrepresented in biobanks.

GMaP, funded by the NCI, consists of six regional networks dedicated to working with groups across the country to advance cancer health disparities research and training. (National Cancer Institute, n.d.) Region 6, coordinated through Fred Hutchinson Cancer Research Center (FHCRC), encompasses Alaska, Washington, Oregon, California, Montana, Idaho, Nevada, Hawaii, Guam, and American Samoa. It is the largest of the six regional hubs and the most ethnically diverse. GMaP Region 6, is comprised of eighteen partner institutions involved in cancer health disparities research within the Region 6 catchment area. Representatives from the partner institutions make up an overarching coordinating committee for the regional initiative. The ongoing, concerted efforts of the coordinating committee provided the regional GMaP program a well-managed, robust infrastructure for the implementation of the biospecimen education program.

In this study, GMaP Region 6 investigators conducted a series of biospecimen education seminars in an effort to increase understanding of the barriers around biospecimen donation among communities in the region. Working with groups that serve various underrepresented populations, the overall goal of this project was to help bridge the gap between researchers, healthcare professionals, and representatives of community organizations by providing reciprocal learning opportunities around biospecimen donation and collection. Toward that end, we implemented a series of educational seminars to: 1) provide education to community organizations on the importance of providing biospecimens to advance cancer research; and 2) to assess the level of readiness of providers and ancillary staff in cancer institutions serving diverse communities to participate in biospecimen collection efforts. Here we report the outcome of that education.

Methods

The GMaP Region 6 coordinating committee collaboratively developed a plan to offer biospecimen educational seminars across the region. In 2012, a request for applications (RFA) was released to the regional partner institutions inviting them to apply to host a biospecimen education seminar. Applicants were asked to submit a four page proposal and accompanying budget. Seven partner organizations in Washington, Oregon, California, Hawaii, and Guam applied; subsequently, all seven projects were approved for funding. Two funded organizations opted to hold two education events; thus, a total of nine biospecimen education seminars took place across GMaP Region 6 between February and August, 2013.

Prior to implementation of the events, partner institution staff selected to conduct the biospecimen seminars at each funded site were required to participate in a train-the-trainer webinar to familiarize themselves with the training materials. The webinar training was hosted by the NCI's National Outreach Network (NON) Community Health Educator (CHE) housed at FHCRC, one of the authors of the *Cancer 101* curriculum. The webinar training included an in-depth review of the training curriculum, pre-post-test instruments and a question and answer period. The webinar participants who were trained in the biospecimen curriculum consisted primarily of NCI's NON CHEs in the GMaP region. NON CHEs act as liaisons between researchers and communities by providing tailored information to the population they serve, which supports efforts to build trust and work with communities to raise awareness about biospecimens for cancer research.

Training Curriculum Content

The training curriculum consisted of the Biospecimen and Biobanking module of the expanded *Cancer 101: A Cancer Education and Training Program (Cancer 101)*. *Cancer 101* is an evidence-based, evaluated education tool that was created in 2002 through a collaboration between the Spirit of EAGLES Community Networks Program, the Northwest Portland Area Indian Health Board's Northwest Tribal Cancer Control Project, and the former NCI's Cancer Information Service – Northwest Region to increase understanding about cancer within Northwest tribal communities.(Hill et al., 2010) The *Cancer 101* curriculum is based on Social Cognitive Theory. By providing trainings to community members, *Cancer 101* trainers help participants build self-efficacy around cancer knowledge and attitudes, and then set behavioral goals to modify risk factors for cancer so that they can work to change behaviors. As participants adopt new and healthier behaviors, this causes changes in both their own person, but also in their environment.

In 2011, the NON CHE at FHCRC updated and expanded the original *Cancer 101* curriculum to include a Biospecimen and Biobanking module.(Briant, Garrett Hill, & Lopez, 2011) This module defines what biospecimens are, how they are collected, and describes why biospecimens are important in research. It also explains the ethical, legal, and social considerations related to tissue and sample donation as well as how a donor's personal and medical information is protected. The module was tailored for GMaP regional use and standardized pre- and post-assessments were developed.

Theoretical Approach

We utilized a near-peer teaching model to train researchers, healthcare professions, and representatives of community organizations through the biospecimen education seminars. Near-peer relationships are characterized by the pairing of individuals who are slightly more advanced in learning and/or training with individuals who are less advanced. Studies find that peer-led instruction is effective in increasing student learning. Both leaders and students benefit from the enhanced learning experience. (Brownell & Swaner, 2010; Cracolice & Deming, 2001; Lave & Wenger, 1991) Peer leaders increase their understanding of the subject matter, and develop an increased sense of responsibility and confidence. In fact, when educational seminar participants at one site were polled about what they would do with the information they received, several concrete examples for advancing knowledge in their own learning environments and agencies were provided. This type of training holds promise for not only advancing the understanding of biospecimens and their uses, but for increasing knowledge, responsibility, and confidence of the trainers.

Participant Recruitment/Informed Consent

An overall goal of the biospecimen education seminars was to provide information and education about biospecimens to people who engage with community members. Each institution was asked to provide an overview of their target audience and recruitment strategies in their proposal. These strategies were used by staff who were responsible for planning and implementing the seminar at each site. All of the funded institutions recruited both community organization representatives providing services to diverse communities, and health professionals to participate in their local education seminar. Recruitment methods for participants consisted of email notifications, promotional flyer distribution, and word of mouth.

Biospecimen Education Seminars

Biospecimen education seminars consisted of mixed audiences of health care providers, health care professionals, and representatives from community organizations. In order to ensure that the biospecimen educational seminars were consistently implemented across the region, the same presentation slides and pre/post assessments were used at all the education seminars across all sites. The NON CHE from FHCRC facilitated or co-facilitated 6 of the 9 biospecimen education seminars. The other 3 seminars were facilitated by two NON CHEs from other sites. An informed consent statement was read aloud prior to the start of the training. Participants were informed that their participation in the training was voluntary and that they had the option to skip questions they did not feel comfortable answering on the pre/post assessments. Biospecimen education seminars typically lasted between two and three hours.

Assessment of the Biospecimen Education Seminars

In all seminars, pre- and post-assessments were administered to document changes in awareness, knowledge, and intention to promote collection of biospecimens among participants. Due to limited resources, pre/post data was collected with a computerized audience response system (ARS) at the majority of seminars (7 of the 9). ARS allowed

matching of pre/post by participant, but data was anonymous which made the collection of data beyond the training sessions unfeasible. Pre-and post-assessments were administered to measure participants' knowledge about biospecimens and biobanking, including: types of biospecimens, uses for biospecimens, the informed consent process, and biobank, or biorepository, locations. Attitudes toward biospecimen donation were also measured including perceived barriers to donation and likelihood of donating.

Demographic variables collected on the pre-assessment included gender, age, education, race/ethnicity, and occupation (health care provider, health care professional or non-health care provider). Respondents who self-identified as a health care provider (physician or nurse) or health care professional (health educator, social worker, etc.) were also asked how often they talk to patients/clients about biospecimen donation.

Knowledge about biospecimens, biobanking and informed consent was assessed through seven agree/disagree/unsure questions. Participants were asked if cells, blood and urine are considered biospecimens; if biospecimens help researchers learn how to treat cancer; and if a person's tissue removed during surgery can be stored for future use. Participants were also asked to answer a multiple choice question asking why donating biospecimens is important. The multiple choice answers included: a.) to look for ways to prevent illness (like cancer, diabetes, heart disease); b.) to develop tests to detect specific types of illnesses; c.) to find ways to target treatments to improve survivorship from illnesses; d.) all of the above; and e.) none of the above. Knowledge about the informed consent process was assessed by two agree/disagree/unsure questions including whether or not a person who donates his/her tissue is able to decide what kind of research the sample is used for and if informed consent is a one-time information session.

Participants' attitudes about biospecimen donation were assessed by responses to agree/disagree/unsure questions. Participants were asked if biomedical studies can help future generations by advancing knowledge on how to fight diseases; if by taking part in a biomedical study they will be helping others; and whether or not they would participate in a research study if asked to donate a biological sample or biospecimen (such as blood, urine, saliva, cheek cells or tissue). On the post assessment, respondents who self-identified as a health care provider (doctor or nurse) or health care professional (health educator, social worker, etc.) were asked how often they would talk to patients/clients about biospecimen donation. All study materials were approved by the Fred Hutchinson Cancer Research Center Institutional Review Board.

Analysis

To analyze the knowledge questions and intention to donate or talk to patients, we used McNemar's exact test for paired binary data.(Agresti, 2014) We coded the responses to the knowledge questions as correct or incorrect. For the intention to donate we combined strongly agree and agree into a single category and undecided, disagree and strongly disagree into a single category. Similarly with intention to talk to patients, we combined always, often and sometimes into a single category and rarely and never into a single category.

To determine an overall knowledge score we averaged the correct/incorrect answers of the knowledge questions, (correct answer=1; incorrect answer=-1). If a participant had missing values for any of the questions, their knowledge score was marked as missing. To determine if knowledge score varied by pre and post-assessment and occupation, we fit a linear mixed effects model with fixed effects for assessment period, occupation, training state, assessment period by occupation, assessment period by training state/territory, gender, age and education. To account for repeated measures, we included a random intercept for each subject.(Faraway, 2006).

All analyses were conducted using the R programming language.(R Development Core Team, 2011)

Results

Nine educational seminars took place across GMaP Region 6. Table 1 summarizes the locations and number of participants. California had the largest number of participants, followed by Hawaii. One of the partners in California offered two educational sessions. Two educational sessions took place in Hawaii, but they were hosted by two different partners. A total of 255 individuals attended the sessions and 235 participants completed both pre- and post-assessments.

Table 2 shows the characteristics of participants. The majority were females aged 30 to 59. Most participants had a higher education degree, and they were evenly distributed in terms of being a health care professional (50.2%) or not (49.8%). Over half (61%) of attendees identified themselves as members of an underrepresented group.

Table 3 indicates the pre- and post-assessment responses to the knowledge questions. Overall, there were significant increases in all knowledge variables except biomedical studies helping future generations, and donating biospecimens would help others. Both of these were rated highly in the pre-assessment as well as the post-assessment. Table 3 also shows the pre and post assessment by health care providers compared to non-health care providers. In pre-assessment, health care providers were more likely to know that informed consent may involve multiple consent forms, and more likely to believe that many underrepresented individuals had a fear or distrust of the medical system. At post-assessment, health care providers significantly increased their scores on two questions (individuals decide what the samples are used for, and informed consent is a one-time process; both false), while non-health care providers increased their scores significantly on four items.

Table 4 indicates differences between pre- and post-assessment in terms of intention to participate in a research study where biospecimens are being collected. There was a significant difference between pre- and post-assessments with more participants strongly agreeing and agreeing they would participate. Further, after having completed the training, significantly more health care provider and health care professional respondents stated they would talk to patients/clients about biospecimen donation.

When reviewing the overall difference between the pre- and post-assessment of the knowledge variables controlling for age, gender, and education, the difference was significant ($p=0.007$).

Discussion

In this study where numerous underrepresented population members were included, the training in the importance of providing biospecimens increased knowledge, intention to donate, and intention to talk to patients about donation. Previous studies also have demonstrated an increase in knowledge and intention to donate among underserved groups trained in the importance of biospecimen donation.(Gao et al., 2014; Tong et al., 2014)

Study participants across all nine sessions in GMaP Region 6 showed a lack of initial knowledge about biospecimens and biospecimen collection. Of eight questions about knowledge, post-assessment differences were significant in six of the areas. Many of the knowledge questions that had poor pre-assessment knowledge focused on the rights of participants in biospecimen collection. For example, 49.6% of respondents thought that the Human Subjects Boards could address all aspects of biospecimen collection in one “informed consent” session. The use of biospecimens is complex and presents complicated issues, such as ownership, genetic testing, future uses, and protection of patient rights by Human Subjects Boards.(Beskow & Dean, 2008; Budimir et al., 2011; Jimmie B Vaught et al., 2007; Yassin et al., 2010) A large proportion of our respondents at pre-assessment (55.1%) believed that a person who donates biospecimens always has the right to decide any uses of the specimens. Again, this varies by Human Subjects Boards.(Budimir et al., 2011) Increasingly, participants’ biospecimens are placed in a repository under the stewardship of a researcher who many decide the future uses of the biospecimen. (Hughes, Barnes, & Watson, 2010)

Several studies have found that members of minority groups express high willingness to participate in biospecimen donation.(Ralph V Katz et al., 2006; Wendler et al., 2005) However, diverse groups remain underrepresented in research studies that involve biospecimen collection (G. Corbie-Smith, Thomas, & St George, 2002; G. M. Corbie-Smith, 2004; Hussain-Gambles, Atkin, & Leese, 2004). Barriers to participation are varied and may also vary by the specific population in which such requests are made. Among African Americans, for example, there is a strong fear of exploitation by researchers and the biomedical system (G. Corbie-Smith et al., 2002; G. Corbie-Smith et al., 1999; R. V. Katz et al., 2007). Some American Indian/Alaska Natives have expressed a distrust of studies funded by the US government, and a fear of lack of autonomy over their samples, or have cultural and spiritual beliefs about keeping the body intact for burial.(Buchwald et al., 2006) Additionally, several underrepresented groups have demonstrated a fear of participation due to lack of transparency and low comprehension of the informed consent process.(G. Corbie-Smith et al., 1999; Shaw, Robinson, Starks, Burke, & Dillard, 2013; Ulrich et al., 2013)

Surprisingly few participants (71.6%) were aware that many underserved individuals would not participate in biospecimen donation because of fear or distrust of biomedical research. In discussions during the seminars, efforts were made to acquaint the participants with the

more egregious examples of unethical biomedical research (e.g., Tuskegee, research on prisoners, Henrietta Lacks); by the post-assessment, a significant increase was seen in the number of participants who understood the examples of distrust of the biomedical enterprise.

Interestingly, there were differences in both pre-assessment and post-assessment between health care providers and non-health care providers. Health care providers were more likely than non-health care providers to know that informed consent could be a multi-stage process at baseline; they were also more likely to know that many people fear or distrust biomedical research. At post-assessment, however, there were significant changes among health care providers in terms of those two variables, suggesting that health care providers had much to learn. Further, there were significant increases in knowing that biospecimens help researchers learn how to treat cancer, and that individuals did not always get to decide for what their samples were used. This suggests that health care providers too have much to learn about biospecimen donation.

It was not so surprising that non-health care providers increased significantly more knowledge compared to health care providers. One might expect health care providers to be more familiar with the field than non-health care providers. Nevertheless, there were areas of non-significant change. Perhaps most striking was significant change in the knowledge that many people have a fear or distrust of biomedical research, with a 22 percentage point change between pre- and post-assessment. The other factors (definition of biospecimens, removal of tissue during surgery, and informed consent) are more likely to be known by health care providers who work in the medical field.

As noted, a significant number of health care providers participated in this study (50.2%). At baseline, very few (20.7%) “always” or “often” talked to their patients about biospecimen donation. This may explain part of the lack of minority participation in biobanking programs, as some studies have shown that members of minority groups demonstrate high willingness to participate in biobanking programs, but are not engaged or asked to participate in biospecimen donation by clinicians; thus participation among these groups remains low. (Durant et al., 2007; Hagiwara et al., 2014; Rodriguez, Torres, & Erwin, 2013; Wendler et al., 2005) After the seminars, however, the percentage of health care providers who intended to always or often speak to patients was 49.5%, a significant increase. Other studies have found similar results after training (Dang et al., 2014; Gao et al., 2014; Tong et al., 2014) however, there is a dearth of studies examining the actual practice of providers after training in providing content about biospecimens.

A number of studies have shown that training individuals on the processes and benefits of biospecimen donation may increase both intention and actual participation in donation. (Dang et al., 2014; Gao et al., 2014; Luque et al., 2012; Rodriguez et al., 2013; Tong et al., 2014) Such findings support the underlying assumption of this study. If underrepresented groups can increase their knowledge of the benefits of biospecimen donation, if they are informed in a culturally relevant way, and if they are assured that their tissue will be treated with respect and integrity, they are likely to be better prepared to donate. (Wendler et al., 2005)

There is little doubt that biospecimen donation is an essential part of progress in cancer research and treatment. Equally important is the notion that biospecimen donation must represent the entire range of population types in the United States; this includes not only NHW, but also racial/ethnic minorities and other underrepresented populations. Without representation, a sizeable portion of the US population will remain isolated from the potential benefits of treatment of diseases such as cancer. This representation is critical to increasing the rigor and impact of studies aimed at better understanding the biological basis of cancer, and developing the drugs that will benefit all members of our society.

Although this work did not include an examination of whether or not underserved individuals were likely to donate biospecimens, it has value in examining the knowledge and intention of intermediaries who can have an influence on the underserved. If health care providers, professionals, and representatives of community organizations understand the various aspects of biospecimen donation and are able to transmit accurate information to the underserved, it is more likely that the underserved will make informed decisions as to whether or not to donate biospecimens.

GMaP Region 6 serves the most diverse populations of all the GMaP hubs and we were able to extend the educational seminars from Latinos in Washington State to Latinos, Asians, and Pacific Islanders in California, Asian and Pacific Islanders in Hawaii, and Chomorro and Pacific Islanders in Guam. This biospecimen education effort supports a concept underlying the GMaP regional networks—researchers in the region are able to advance cancer health disparities research and training by reaching the constituencies they serve.

This study has a major limitation. Since pre/post assessment was done at the beginning and end of each seminar session, we were unable to measure actual change in behavior, relying only on perceived intention to change. Intention does not always result in behavior change. Unfortunately, lack of resources prevented us from following up with trained individuals to ascertain if their intention was related to subsequent practice. Future strategies would be to contact trainees some time after the seminars to assess the congruence of their behavior with intention. This is especially true for the health care providers who have opportunities to talk to underrepresented patients about the importance of biospecimen donation. Nevertheless, the seminars were successful in increasing knowledge and building awareness around the importance of biospecimen donation and collection.

Conclusion

A series of educational seminars in the importance of biospecimen donation and collection was held throughout GMaP Region 6, the largest and most diverse of the GMaP hubs in the United States. Educational seminar sessions were preceded with a pre-assessment and concluded with a post-assessment. There was a significant increase in knowledge in six of nine knowledge questions and in intention to donate samples and to talk to patients about biospecimen samples. This type of education may ameliorate some of the distrust of biomedical research experienced by racial/ethnic minorities and, in turn, increase needed minority representation in biospecimen collection. Implications of this study are that education in the importance of biospecimen collection leads to increased intention to talk to

underrepresented patients and community members about the importance of biospecimen donation to increase the development of treatment for cancer. Future research should follow trained individuals to ascertain that intention to change translates into actual change. It is also necessary to examine biospecimen repositories to determine if samples are being banked from the underrepresented. This study initiates a first step in the process to promote awareness of the important role biospecimens in cancer research and ultimately support biospecimen donation among the underrepresented. Next steps include follow-up with partner institutions in the GMaP region to see if this initial series of seminars led to increased implementation of culturally relevant educational seminars on biospecimens in their local communities.

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Table 1

Location and Number of Trainees

Location (Number of Seminars)	Number of Participants (n)	% of total participants
<i>CALIFORNIA (3)</i>	92	36.1
• San Francisco State University	33	
• Pacific Island Health Partnership	10	
• Pacific Island Health Partnership	49	
<i>GUAM (1)</i>	22	8.6
• University of Guam	22	
<i>HAWAII (2)</i>	87	34.1
• University of Hawaii	42	
• Papa Ola Lokahi	45	
<i>OREGON (1)</i>	39	15.3
Oregon Health and Science University	39	
<i>WASHINGTON (2)</i>	15	5.9
Fred Hutchinson Cancer Research Center	15	

Table 2

Characteristics of Participants at Baseline *

Characteristic	n	(%)
Gender		
Female	171	(73.4)
Age		
18 – 29	57	(24.7)
30 – 59	114	(49.4)
60 +	60	(25.9)
Education		
High School or less	35	(14.9)
Some College or College Degree	125	(53.2)
Advanced Degree	75	(31.9)
Occupation		
Health Care Professional	118	(50.2)
Not in Health Care	117	(49.8)
Race/Ethnicity		
Hispanic	20	(11.6)
Black or African American	3	(1.7)
American Indian or Alaskan Native	2	(1.2)
Pacific Islander	47	(27.2)
Non-Hispanic White	67	(38.7)
More than one of the above	34	(19.6)

* Numbers may not add to 235 depending on number of individuals who responded to particular questions.

Table 3

Changes in Knowledge from Pre- to Post-Assessment*

Knowledge Question	Pre-Assessment			Post-Assessment			Pre-Post		
	HCP correct	Not HCP correct	P-value	HCP correct	Not HCP correct	P-value	HCP P-value	Not HCP P-value	
Biospecimens refer to biological materials, such as cells, blood, and urine used for research.	92.8%	86%	0.1302	94.4%	97.1%	0.4989	0.999	0.0002	
Biospecimens play an important role in helping researchers learn how to treat cancer.	94.7%	96.4%	0.7483	99.1%	99%	0.9999	0.0313	0.625	
A person's tissue, such as cancer cells removed during surgery, can be stored for future research.	86.4%	83.2%	0.5781	93.5%	94.2%	0.9999	0.1435	0.0034	
If a person donates their tissue or blood to a study, they always get to decide what the samples are used for.	56.2%	53.1%	0.6885	72%	57.8%	0.042	0.0033	0.7201	
Informed consent is a one-time information session.	60.2%	38.8%	0.0015	72.5%	52%	0.0027	0.0243	0.029	
Biomedical studies can help future generations by advancing knowledge on how to fight a disease.	95.6%	96.6%	0.7463	98.2%	98.1%	0.9999	0.6875	0.6875	
By taking part in a biomedical study, I will be helping others	87.7%	92.2%	0.2788	90.7%	96.1%	0.1673	0.6291	0.125	
Many people will not participate in a biomedical study because of fear or a distrust of biomedical research.	77.6%	65.5%	0.0581	88.9%	87.3%	0.8319	0.0023	0.0001	

* The percent answering correctly for each knowledge question in the pre and post-test by occupation (health care provider (HCP) and not HCP). P-values for the pre and post-test answers are calculated using Fisher's exact test. The p-values for the pre-post test comparison were calculated using McNemar's test for paired binary data using the number of discordant pairs for each question (data not shown). For the purpose of the analysis, 'not sure' was recorded as answering incorrectly.

Table 4**Intention to Donate and to Talk to Patients ***

Intention Item	Pre-test n (%)	Post-test n (%)	p value
“I would participate in a research study if asked to contribute a biological sample.” (Health Care Professionals)			
Strongly Agree / Agree	80 (70.2)	86 (80.4)	
Undecided	30 (26.3)	18 (16.8)	
Strongly Disagree / Disagree	4 (3.5)	3 (2.8)	0.0768
“I would participate in a research study if asked to contribute a biological sample.” (Non-Health Care Professionals)			
Strongly Agree / Agree	87 (75.7)	86 (82.7)	
Undecided	24 (20.9)	14 (13.5)	
Strongly Disagree / Disagree	4 (3.5)	4 (3.8)	0.146
“How often do you/will you talk to patients about biospecimen donation?” (Asked only of health care professionals)			
Always / Often	28 (20.7)	132 (76.8)	
Sometimes	12 (8.9)	47 (27.3)	
Rarely / Never	107 (79.2)	40 (23.3)	<0.0001

* P-values are calculated using McNemar’s test for paired binary data using the discordant pairs for each question (data not shown). For the purpose of this analysis, strongly agree is combined with agree; undecided, disagree and strongly disagree are combined. Similarly, always, often and sometimes are combined; rarely and never are combined.