Cancer Patient Perceptions about Biobanking and Preferred Timing of Consent

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Little is known about how cancer patients feel about donating their tissue, especially in a multiethnic population. Structured interviews were conducted with 30 patients recently diagnosed with cancer, referred to the study by six cancer surgeons and oncologists and by other patients in the study. The participants reported a variety of cancers, and the sample reflected the racial distribution of Hawai'i, including Caucasians (23%), Native Hawaiians and Pacific Islanders (27%), Asians (37%), Hispanics (7%), Native Americans (3%), and African Americans (3%). The interview questions and analysis were guided by the Framework Approach, with interview questions based on pre-set aims. Findings suggest that most cancer patients would donate cancer tissue to science, especially if informed that doing so could help researchers find causes of and cures for cancer. Patients varied on when in their cancer journey they would be most receptive to being asked for a donation, however two-thirds thought they would be more receptive if approached after surgery. Only three of the 30 patients said they would want to be re-consented each time their tissue is requested for research. They identified their physician as the preferred messenger regarding tissue donation. No obvious differences were seen by race. Findings confirm those of other researchers who have reported broad support for biobank participation if informed consent and confidentiality could be assured. Given that the physician was seen as the key messenger about biobanking, more education is needed around cancer tissue collection for physicians, as well as for cancer patients.

Introduction

A HUMAN BIOREPOSITORY IS A FACILITY that stores human specimens (e.g., tissue, blood, urine, and sputum) and provides them to researchers studying the causes and cures of disease. Early biorepositories consisted of small collections of specimens for specific research projects. In the past 30 years, governments and commercial entities have formed large institutional and population-based biorepositories.¹

Whether biorepositories gather tissue attained during surgery, cord blood from newborns, or blood, hair, sputum, or other materials from volunteers, biorepositories in the US must obtain consent to use this tissue for research purposes from live donors or their legal representatives. Informed consent processes must ensure that participants understand the nature of a biorepository as a place that stores specimens for potential use in research. It should convey that biospecimens may be stored indefinitely and shared widely, and that the exact use of the specimen in research may be unknown at the time of consent. Donors also must be informed of protections to ensure the privacy and confidentiality of

their specimens and any associated information, their rights and options for discontinuing participation, and their access to research results.²

For cancer patients, specimens are surgically obtained during a biopsy or treatment for removal of a tumor. In customary medical practice, pathology specimens are retained by hospital laboratories for 10 or more years, typically in the form of slides and paraffin blocks, as required by accreditation standards.³ Tissue removed but not selected as part of the pathology specimen also must be retained for a minimum of 2 weeks.³ Advances in biorepository capacity have increased options for storing excess tissue for research. Ideally, specimens designated for future research are frozen soon after removal from the body and pathologic review to preserve optimal tissue integrity.⁴ With cancer, tissue of interest to future researchers may be removed before a diagnosis is established. Thus, hospitals may choose to approach cancer patients postoperatively for consent to store excess tissue in a biorepository. If they do not consent to having their tissue banked for future research, stored excess tissue is then discarded.⁵

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The National Cancer Institute (NCI) publishes best-practice guidelines for biospecimen resources, including guidance on technical aspects of biobanking (e.g., specimen collecting, processing, storing, retrieving, and dissemination) and for ethical management and governance.⁶ In terms of informed consent, the guidelines recognize that patients may be too concerned about their pending diagnosis or treatment to fully comprehend a pre-surgery request to donate tissue. Guidelines also recommend that biorepositories establish two advisory committees, one that provides strategic guidance on biorepository resource development, and another that reviews and approves requests for specimens in light of the scientific merits and ethical concerns of each proposal.

In developing its biorepository, The Queen's Medical Center (QMC) in Honolulu, Hawai'i supported research on cancer patient perceptions of biobanking for cancer research. QMC is one of 21 hospitals in the National Cancer Institute Community Cancer Centers Program (NCCCP), and the development of biorepositories that comply with NCI best-practice guidelines is a deliverable for NCCCP hospitals (<http://ncccp.cancer.gov/>). QMC is the largest civilian medical center in the Pacific, serving both as a primary and tertiary referral treatment site for cancers in Hawai'i and the greater Pacific region. In Hawai'i, Asians and Pacific Islanders comprise about 70% of the population. While several studies have examined patient and community perceptions of biobanking,^{4,7-15} very few have been performed on Hawai'i's multi-cultural population.^{16,17} The purpose of this study was to ask cancer patients about their preferences for consent timing, about who should approach them about biobank donations and their thoughts on biospecimen research participation.

Methods

Sample

Structured interviews were conducted with 30 patients. To accrue sample, six cancer surgeons and oncologists were approached and agreed to refer English-speaking adult patients with cancer tissue removed in the past 2 years. This approach was chosen as the most expeditious way to learn about patient perceptions while QMC was developing its consenting protocol. Physicians were provided packets that included a recruitment flier, a brochure that introduced the concept of biobanking for research, and a consent form. Some physicians obtained written consent from patients (forwarding the consent form to the researcher), others provided packets to potential patients, while others only distributed the recruitment flier. Physicians provided the researcher with contact information for individuals willing to participate. Additionally, several participants who completed interviews referred other patients to the study.

The study was approved by the Western Institutional Review Board (IRB) and by the IRBs affiliated with the University of Hawai'i, the Native Hawaiian Health Care Systems, and QMC. None of the authors had any conflicts of interest.

Measures

The interview questions and analysis were guided by the Framework Approach, in that interview questions were

based on pre-set aims.¹⁸ They were reviewed by a national expert in protection of human subjects related to biobanking, as well as biorepository physicians and staff at QMC. Interview questions included: 1) What were you told about what happens to your cancer tissue after it is removed during surgery? 2) What do you think about donating part of your cancer tissue to science? 3) Who should ask (you) about donating your tissue? 4) Thinking back on your cancer journey, when would be the best time to be asked to donate your cancer tissue to science? 5) Once your tissue is in the biorepository, would it be all right for the biorepository to share your tissue with any researcher whose study is approved by the governing committees that review scientific merits and ethics, or would you want to be asked for your permission each time your tissue is requested for a study? and 6) What advice would you give the biorepository about communicating with donors? Interviews were completed over a 2-month period. All interviews were recorded for transcription purposes.

Participants were asked to complete a demographic questionnaire capturing age, gender, race, marital status, employment, health insurance type, cancer type, and year of diagnosis. Participants were provided with a \$25 gift certificate to a local sundry store in appreciation of their time.

Data analysis

All interviews were transcribed, and demographic data were managed in MS Excel®. Identification numbers (rather than names) were used in the transcripts and database. Following the five steps of the Framework approach to analysis (familiarization, developing a codebook, coding, charting, and interpretation), two of the investigators (KLB, JUT) read the transcripts to become familiar with the raw data and identify key ideas and recurrent themes derived from the aims of the study and by the respondents.¹⁷ A codebook was created, and transcripts were systematically coded by the researchers. There was disagreement between the reviewers on approximately 5% of the codes, and these discrepancies were resolved through discussion.¹⁹ The data then were charted (i.e., rearranged and synthesized) into core themes. In the interpretation phase, key quotes were identified that illustrated the themes. Findings from the study were shared with physicians and other clinicians associated with the QMC cancer center and biorepository, who assisted in contextualizing the findings and recommending next steps.¹⁹

Results

A total of 35 cancer patients were referred to the study, 27 by physicians and eight by patients who completed the interview. Of those referred, two did not have working phones, one did not return the researcher's calls, one could not communicate in English, and one declined to participate during the phone screening. Gender, ethnicity, and cancer type distributions were similar in the referred and completed groups (Table 1).

Of the 30 participants completing the interview, the mean age was 64.1 years (range 44 to 85 years), 24 (80%) were female, 21 (70%) were married, and 17 (57%) had completed at least 2 years of college. Fourteen (46%) of the individuals were retired, 14 (46%) were employed, and two

TABLE 1. CHARACTERISTICS OF THE SAMPLE

	Referred N (%)	Interviewed N (%)
Referred by		
Physician	27 (77%)	23 (77%)
Another interviewee	8 (23%)	7 (23%)
Gender		
Male	8 (23%)	6 (20%)
Female	27 (77%)	24 (80%)
Ethnicity		
Caucasian	8 (23%)	7 (23%)
Native Hawaii/Pacific Islander	8 (23%)	8 (27%)
Asian	15 (42%)	11 (37%)
Hispanic	2 (6%)	2 (7%)
Native American	1 (3%)	1 (3%)
African American	1 (3%)	1 (3%)
Type of cancer		
Breast	10 (29%)	10 (33%)
Gynecologic	9 (26%)	9 (30%)
Lung	13 (36%)	8 (27%)
Thyroid	2 (6%)	2 (7%)
Prostate	1 (3%)	1 (3%)
Educational attainment		
High School		4 (13%)
Some college		9 (30%)
College grad		17 (57%)
Primary Insurance		
Private		16 (53%)
Medicare		13 (43%)
Medicaid		1 (3%)

were on temporary disability. Sixteen (53%) had private health insurance, 13 (43%) were on Medicare, and one was on Medicaid. The racial distribution of the sample reflected that of Hawai'i, including Caucasians (23%), Native Hawaiians and Pacific Islanders (27%), Asians (37%), Hispanics (7%), Native Americans (3%), and African Americans (3%). The participants reported a variety of cancers, including breast (33%), gynecologic (30%), lung (27%), thyroid (7%), and prostate (3%); this distribution reflected the specialties of the referring physicians. Eighteen individuals (60%) were diagnosed in the past 12 months, and 12 (40%) were diagnosed more than a year ago.

Despite this variety of patients, responses to most questions were rather homogenous, and thematic saturation was reached well before the 30 interviews were completed. Responses are presented by topic area, and also summarized in Table 2.

Stored tissue from biopsy or surgery

Of the 30 participants, 26 (87%) did not remember being told what happened to their cancer tissue, remarking, "I don't remember a conversation about this," "They said they would sent it to pathology, but nothing about what happens after that," and "I assume they just throw it away." Three participants noted finding out indirectly that tissue was kept, as exemplified by this quote: "I did a genetic test, and they told me that they had my sister's tissue from several years ago. That's when I found out they save tissue." Five participants had been part of other research studies and were

not surprised to learn that tissue was kept, and one had agreed to donate tissue as part of a research study when she was diagnosed. She reported:

For me, I actually experienced it. I had someone come in and ask if they could keep my lung tissue, and of course I said, "Of course." It was no problem. I took it as an opportunity. It was a researcher, and I said "Look I don't mind people looking at my tissue or lung, but I want to see it too." So they arranged for a transporter to take me down to the lab and I saw it, and I was awed by it. It was a great experience and everyone was so nice.

Donating tissue to science

All 30 participants were agreeable to donating their cancer tissue to research. Upon elaboration, 11 said they would donate to help others, especially cancer patients, as shown in this quote: "What a cancer patient goes through, why not? If this can help somebody else, why not? And it makes you feel like you're contributing and doing something." Eight noted that research was "a good cause," and six hoped their donation would help researchers "find a cure." Two noted that "it feels good to help." Six gave more passive reasons for donating, including "I'm OK with it," and "It's out already, so why not." Three of the 30 participants qualified their support with concerns about privacy and ethics, as exemplified by this quote: "I am happy to contribute my tissue, as long as everything is kept confidential and the process is ethical."

Despite the different ethnicities represented in the sample, no participant mentioned that cultural or religious beliefs would present a barrier to donating their cancer tissue. However, two Native Hawaiian participants alluded to the traditional Native Hawaiian belief that one's mana (spirit or power) resided in all body parts. In traditional society, placentas were buried under a bush or tree, finger nail and hair clippings were hidden, and bones of the deceased were interred in secret places so that they could not be used by evil-doers to cast spells or otherwise harm the individual or family.²⁰ These two participants elaborated by saying that they would try to dissuade Native Hawaiian friends from seeing cancer tissue in this light, noting the Hawaiian value of helping other.

Who should be asking for the donation?

Of the 30 respondents, 26 thought the physician should ask them for the tissue donation. For patients who had several physicians (e.g., a surgeon, medical oncologist, and radiation oncologist), the general consensus was "the one I have the best rapport with." When reminded that the physician might be too busy to obtain consent for the donation, 24 patients qualified their statement by saying "the doctor should mention it first," and let them know that another practitioner would follow-up. Of those that did not insist that the physician ask first, one said, "whoever asks, they must represent the hospital, and it must be face-to-face," another said "the researcher," and two said, "several people should ask me at different points in the cancer journey." Two patients mentioned that they had been seen by a Survivorship Nurse, and said that this would have been a good person to talk with about donating tissue. Six noted that "it should be someone who can explain everything and get the ideas across about the benefits."

TABLE 2. MAJOR THEMES BY TOPIC AREA

	N (%)
What were you told about the storing of your cancer tissue from biopsy or surgery?	
Did not remember being told what happened to cancer tissue	26 (87%)
Found out indirectly that tissue was kept.	3 (10%)
Had participated in research in the past, so not surprised that tissue was kept.	5 (17%)
Was approached in physician's office to donate tissue to a specific research study, and agreed	1 (3%)
Would you be willing to donate your excess cancer tissue to science?	
Yes, would donate	30 (100%)
Motivated to help others, especially cancer patients	11 (37%)
Felt research is "a good cause"	8 (27%)
Hoped their donation would help researchers find a cure	6 (20%)
It feels good to help	2 (7%)
I'm OK with it; it's out anyway	6 (20%)
Would donate if concerns about privacy and ethics were addressed.	3 (10%)
Who should be asking for the donation?	
My physician should ask.	26 (87%)
My physician should mention it first, and another practitioner can follow-up.	24 (80%)
Whoever asks must represent the hospital, and request must be face-to-face.	1 (3%)
The researcher should ask.	1 (3%)
Several people should ask at different points in my cancer journey.	2 (7%)
The survivorship nurse.	2 (7%)
Someone who can explain everything and get the ideas across about the benefits.	6 (20%)
Develop educational materials to educate the patient.	5 (17%)
Thinking back on your cancer journey, when is the best time to be asked to donate tissue?	
Before surgery	11 (37%)
First or second post-operative visit	10 (33%)
After treatment is completed	9 (30%)
During survivorship planning	2 (7%)
Would you give overall consent or want to be consented each time a researcher requests to use your tissue?	
Blanket approval	23 (77%)
Re-consented each time a researcher wanted to include their tissue in a study	3 (10%)
Uncertain	4 (13%)
What advice would you give the biorepository about communicating with donors?	
Regular newsletter	23 (77%)
Content: if our tissue led to a cure or helped others.	11 (37%)
Content: if biorepository is meeting its targets for donations.	4 (13%)
Content: number and type of studies using donated tissue	4 (13%)
Purpose of newsletter: to acknowledge donors	6 (20%)

*Responses total >100% as patients gave multiple answers.

One noted that the person reviewing the consent form should mention the risks of consenting. "Patients should know that sometimes tissue has been taken without consent, that some individuals or companies have profited from use of patients' tissue, and that it's the researcher's responsibility to obtain true informed consent from research participants and specimen donors." There were five suggestions to develop educational brochures on tissue donation and to incorporate information about biobanking into existing patient education materials and videos.

Timing of consent

This topic yielded great variation. Eleven (37%) felt they should have been asked before surgery, when they were consenting for the surgical removal of the tumor. Ten (33%) felt they would have been too concerned about the pending surgery to respond to a donation request prior to surgery. They recommended waiting until the first or second post-operative visit, when they understood the diagnosis and treatment plan. Nine (30%) said the physician should wait until after treatment was completed, for example, "after

you're feeling calm, about 3 months after surgery," and "after chemo, about 6 months after surgery." Two felt they should be asked during survivorship planning. Differences of opinion were analyzed by gender, ethnicity, and cancer diagnosis, and no patterns were found.

Blanket consent and re-consenting

Of the 30 participants, 23 (77%) said they would give blanket approval for use of their donated tissue in research, three said they would want to be re-consented each time a researcher wanted to include their tissue in a study, and four were uncertain. The feelings of some of the more ambivalent survivors are reflected in this quote, "I don't need to know. Once it's out, I don't want to think about it." The feelings of those more supportive of research were reflected by the survivor who said, "I don't want a consent form for each study, but I like the idea of the committees that oversee the process; I would trust the experts."

Of the three who wanted to be re-consented, all maintained that the biorepository should be responsible for keeping track of donors, and two said they would be

responsive to annual requests by the biorepository to verify contact information. One respondent who had participated in a cancer research study in another state noted that she had agreed to donate her tissue to that study only. She anticipated being asked to consent to have her tissue used in other studies, and commented that her feelings toward research had changed after she developed trust in her research team. She said:

At the end [of my treatment] I was thinking, "I really do trust my study team, the people I work with." And if they asked me to re-consent for another study, if it's a study by my study team, I will say, "yes" right now. I'm so happy with the University, the system, that I would be willing to go with it. But it's good to have those kinds of options. Wherever I'm at in the process, it's rarely a yes or no. What about the grey areas?

Communication with donors

This question, "What advice would you give to biorepositories about communicating with donors?" proved the most difficult to answer without prompting from the interviewer. In 26 of the 30 interviews, the researcher had to give examples of potential communiqué, including thank you notes, reports of findings, and newsletters. With the mention of a newsletter, 23 (77%) patients said they would appreciate receiving one. As a respondent noted, "It would keep me updated about what's going on. I'm very interested in research." When asked what should be in a newsletter, 11 wanted updates on findings, as reflected in this quote, "It would be wonderful to know if they found a significant finding to help others." Four wanted updates on how the biorepository was meeting its targets for donations and on the number and type of studies using donated tissue. Six noted that a newsletter would be a good way to acknowledge donors, as reflected in this quote: "Yes, it would build confidence in the hospital. It would show appreciation for donors and acknowledge their contributions. And, it might be a good marketing tool to attract other donors." When asked how often they would want to receive a newsletter, three said quarterly, ten said annually, and five said every few years.

Discussion

This study yielded six major findings. First, it appears that very few patients knew that medical centers and clinical laboratories must keep tissue, both malignant and nonmalignant, for a specified period. Second, many cancer patients would be willing to donate their cancer tissue to a repository, especially when they understood that doing so could help researchers find causes and cures for cancer. Third, the patient's physician is a key messenger in the "ask" for the donation. Fourth, patients vary on when in their cancer journey they would be most receptive to donating their tissue to a biorepository. Fifth, it appears that only a small minority of patients would want to be re-consented each time their tissue is requested for use in research. Sixth, donors would appreciate receiving a newsletter that shared general findings.

Findings confirm those of other researchers. Several individual studies, as well as a review of patient and citizen surveys, have found broad support for biobank participation.¹⁴ In focus groups with healthy adults in Florida, Luque

and colleagues found favorable attitudes toward cancer research in general and toward biobanking specifically if informed consent and confidentiality could be assured.¹⁰ Similar to this study, other researchers have found that altruism (wanting to help others), detachment from the tissue ("it's out anyway"), and seeing research as "a good cause" were reasons given for agreeing to donate.^{10,15}

Patients perceive the physician as a key messenger, and this is not surprising. A growing body of literature points to the significance of the "physician ask" in enrolling patients in clinical trials and other research endeavors. Albrecht and colleagues, for example, found that cancer patients were more likely to enroll in a clinical trial if the physician used clear language, built trust, and assured the patient and family of good continuing care.²¹ Work by a Texas university supports the finding that the consenter need not be a physician, but should be someone with excellent skills at consenting patients. They also found that patients approached by first-time consenters were significantly less likely to consent than those approached by seasoned consenters, underscoring the importance of good training of consenters.^{7,22}

There was no consensus among the participants about the best time to approach cancer patients for consent to donate their cancer tissue to science. Only one-third of them felt that consent should be asked prior to surgery. In an analysis of this issue specifically, Hewitt and colleagues outlined several disadvantages of pre-operative consent, including patient anxiety about diagnosis and fears that declining consent may jeopardize the quality of care received.⁵ Other research suggests that individuals waiting for results of a medical exam experience cognitive distraction and lowered recall of medical information than individuals who know their diagnosis.²³ A survey of 574 cancer patients in France who had consented preoperatively to donate tissue to the biobank found significant discrepancies in what the patients remembered about their consent.⁴ Of patients who remembered giving consent, only 62% actually had, and of patients who said they were not asked or declined consent, 32% had actually provided consent. In a study associated with a university-based biorepository, timing of consent was a predictor of willingness to enroll, with enrollment rates higher among patients consented 1 to 30 days after cancer diagnosis vs. those consented pre-diagnosis.⁷ These findings add support to the move from preoperative to postoperative consenting for cancer patients approached to participate in biorepositories, as the majority of patients in this study preferred consent postoperatively. Given that CAP guidelines specify that excess tissue only needs to be retained by laboratories for 2 weeks after the final report is issued, QMC plans to seek consent for biobanking the tissue during this required holding period.

About 90% of the respondents would give blanket consent for use of their tissue in future research, with the understanding that research proposals would be reviewed for scientific and ethical merit by biorepository oversight committees, as well as IRB. Several studies have found that donors agree to surrogate decision-making regarding the use of their specimens in specific research projects. In a survey of 1200 donors to a blood biobank in Sweden, only 12% wanted to review and approve use of their blood in individual research studies, while 86% agreed that the regional research ethics committee could decide for them.⁹ A study of leukemia patients in Canada found that only 10% preferred to be re-consented for each request to use their

banked specimen, 60% preferred one-time consent, and 30% preferred tiered consent, which refers to being given options regarding the types of studies in which stored samples could be used.¹¹ In the US, Chen and colleagues reviewed consent forms of 1300 healthy and ill individuals already participating in NIH studies and found that 85% permitted unlimited future research with their stored biological samples.²⁴ There is evidence to suggest that preference for re-consenting is higher among members of the general public than among patients and research participants. For example, in a population-based survey in the US including 4968 healthy adults, 42% indicated that they would want to be re-consented for each biospecimen-related research study.¹²

None of the participants said they wanted to be informed of personal findings from their tissue. Perhaps this was not mentioned because the interviewer defined biobanking as a method to store tissue for future research on causes of and cures for cancer, which does not suggest a personal benefit to the donor. As recommended by Hanson²⁵ and others, biobanks that expect to provide individual findings to donors must have protocols to manage disclosures and clinical expertise to counsel patients as needed.

This study had a number of limitations. The sample size was small, involving 30 cancer patients. However, we reached thematic saturation relatively early in the study, suggesting that 30 was an adequate sample to hear a diversity of views. The design was to accrue sample evenly across six physicians, but some physicians were more successful at referring patients than others. These physicians may have been able to communicate positive feelings about research and biobanking to patients as they asked them to join the study. Women were over-represented, and patients with some cancers (e.g., gastrointestinal and brain malignancies) were not included, which reflected the specializations of referring physicians. The racial distribution, with high proportions of Asians and Pacific Islanders and small proportions of Hispanics and African Americans, reflects Hawai'i demographics, but may limit generalization of findings to other communities. Finally, people who volunteer for research studies may have more positive views of research in general and be more likely to participate in new research endeavors, such as biorepositories, than patients who do not volunteer.

Findings suggest that cancer patients would be receptive to donating tissue to biorepositories if they are educated on the importance of specimen-based research, are assured of high ethical standards, and are asked by their physician to participate. The study, supported by a hospital in the process of developing a biorepository to support cancer health disparities research, demonstrates the importance of seeking and incorporating patient perspectives on the consenting process for donation of tissue, particularly in a state with a diverse population and pronounced cancer health disparities between ethnic groups. More research on ethnic-specific concerns about research using banked specimens and the development and testing of educational interventions for physicians, as well as patients, is warranted.

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