Privacy, Policy, and Profits: Survey of Patient Preferences for Research on De-Identified Biosamples

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Abstract

This study aims to identify patient preferences to inform ethical frameworks, policies, and technologies for advancing biobanking and precision medicine while balancing competing objectives and priorities. We surveyed 109 American breast cancer patients in 2022 about conditions for receiving research results, how their biospecimens are used, partnerships between nonprofit health systems and for-profit companies, and the distribution of financial returns from research. Survey questions explored the balance between objectives like maintaining de-identification versus receiving research results and other benefits. Patients in our sample generally prefer to be re-identified to receive information about the use of their donated tissue—especially research results. They support public-private partnerships if they speed up new therapies and favor the idea of sharing in financial returns generated from research on their tissue. These insights can inform the development of frameworks and technologies that position patients as key stakeholders in biobanking research.

Keywords: personalized medicine, tissue research, biobanking, return of research results, commercialization of research, patient engagement.

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Introduction

Biobanks–entities that systematically collect and store biospecimens and accompanying data–have proliferated in academic hospitals and other settings over the past several decades (Annaratone et al 2021). In the US, these platforms typically operate on a model that obtains one-time informed consent from patients, treats the institution as the de facto owner of donated specimens, and commits to removing patient identifiers from their donations and related clinical data for subsequent research use (Ivanova and Katsaounis 2022). The removal of identifying information from patient data, including biospecimens, is typically accompanied by prohibitions of re-identification and re-contact of subjects by researchers even in the event of actionable incidental findings (The Common Rule 2018). This restricts the ability to update or clarify consent terms as biospecimen research evolves. This approach contributes to a system in which patients generally do not learn about what happens to their biospecimens or benefit directly from research findings that may be clinically relevant, commercially valuable, or personally meaningful (Gross et al 2021). Requirements for de-identification not only preclude informing patients about the outcomes of studies using their donated biospecimens, but also forgo all potential methods of engagement such as soliciting patient input on changes or additions to research protocols in which they might participate, discussing future uses of their biospecimens and data, or even updating them on the ongoing research and its implications for their health or the broader scientific community (Kass and Faden 2018).

There is a large body of literature that surveys patients' preferences on receiving research results, both primary and incidental (Kauffman et al 2009, Fiallos et al 2017, Bollinger et al 2012, Bollinger et al 2020, Morain et al 2021, Husedzinovic et al 2015). Generally, patients are interested in receiving research findings, with increased interest when results are of a reliable quality and are clinically actionable. However, surveys typically do not frame questions in a way that suggests the need to balance between obtaining information and potentially allowing re-identification. This important consideration—between maintaining patient de-identification and providing access to research results—is often left unexplored.

Emerging technologies, such as decentralized biobanking and blockchain-backed software solutions, offer the potential to reconcile patient privacy with greater engagement in research involving their biospecimens. These tools enable transparency, patient involvement, and accountability, preserving established privacy policies while promoting new forms of inclusion for specimen donors (Castillo-Pelayo 2015). They provide mechanisms for ensuring that patient preferences are considered in decisions about the use of their biospecimens and data. Moreover, they create pathways for dynamic data sharing between research and clinical care, which could enhance personalized treatment options and allow patients to stay informed about research outcomes that may affect their health (Lee et al. 2019; Olson et al. 2014). However, existing regulatory frameworks, notably in the US, hinder the adoption of these advancements. Strict privacy protections, such as those under the Common Rule, prohibit re-identification and re-contact with patients, which limits the ability to update consent or engage patients with new research opportunities or findings. These regulations were designed to protect patient anonymity but now stand in the way of more patient-centered research models that could both respect privacy and foster ongoing involvement (Gross et al. 2021). As institutions expand biobanking and precision medicine, it is crucial to understand patient preferences and ensure that any new frameworks balance privacy protections with the need for transparency and inclusion in research.

Another closely related area involves the commercial activities of biobanks, 87% of which are public sector infrastructure owned by governments, academic institutions, and non-profits (BCC

Publishing Staff 2022). While the direct engagement and transparency discussed are essential for trust and ethical operations, the commercialization of biospecimens and their derivatives via public-private partnerships (for example, with pharmaceutical companies) introduces additional complexity. In fact, surveys indicate that patients have mixed feelings about the involvement of third-party commercial partners in biobanking research (Nicol et al 2016, Critchley et al 2021, Critchley et al 2015, Haddow 2007). Yet, making biobanking economically sustainable remains a significant challenge (Henderson et al 2019, Rao et al 2019, Vaught 2013). Understanding how to maintain financial viability and maximize the utility of specimen collections while respecting patient preferences is crucial. Partnerships between the private sector and nonprofit academic medical institutions, broadly considered essential to the translation of new discoveries, may be equally necessary for the solvency of biobanks. However, these partnerships must be navigated carefully to preserve trust, avoid reputational damage, and ensure ethical integrity.

Designing a system that provides transparency and accountability to patients while fostering more effective biobanking business models is a major challenge. We argue that patient preferences can inform institutional policies and may help illuminate a path through ethical challenges. They may do so by guiding decisions toward solutions that balance competing goals in ways that are aligned with patient preferences, made possible by new platform technologies with the potential to embed the inclusion of donors as stakeholders in ongoing specimen collection and research activities.

In this study, we surveyed 109 patients from across multiple breast cancer clinical sites within the University of Pittsburgh Medical Center (UPMC) network—which includes Magee-Womens Hospital and other campuses, and maintains an established institutional breast-cancer biobank pipeline— to examine patient preferences regarding key policy scenarios involving competing objectives and priorities in biobanking research. Specifically, we aim to answer the following research questions:

1) What are patients' preferences regarding notification about and influence over decisions on how their donated tissues and tumors are used?
2) Do patients prefer maintaining strict privacy protections through de-identification, or are they willing to allow re-identification to gain access to research results?
3) In collaborations between nonprofit academic institutions and for-profit companies, do patients prefer limiting private-sector profits derived from their biospecimens, or are they willing to accept profit-making if such collaborations accelerate the development of new therapies?
4) Do patients prefer financial returns from commercially successful research to benefit individual donors whose biospecimens directly led to breakthroughs, or do they favor broader sharing among all donors?

The questions were specifically designed to illustrate the balance between ethical and practical objectives in biobanking policies. Specifically, we framed our survey questions to capture how patients balance competing objectives, such as privacy vs. access to research results, preventing companies from profiting from donated specimens vs. advancing new therapies, and preferences among various approaches for distributing research profits (potentially including the donors themselves). Importantly, this survey did not introduce potential decentralized biobanking technology solutions, allowing a baseline assessment of patient preferences in this study

population. Our approach not only reveals patient preferences concerning institutional policies but also contributes to the broader discourse on patient-centered biobanking policymaking in the United States and elsewhere. Additionally, it offers preliminary evidence to inform the development of ethical frameworks and technology platforms that align with patient preferences.

Methods

Study Setting

This cross-sectional study occurred among patients presenting to breast cancer clinical sites within one academic, urban health system. This site features one of the largest breast cancer biobanks in the United States. While we used a convenience sample, the selection of breast cancer patients was intentional, occurring alongside an in-depth case study of the respective biobank (protocol 19060196), for which consent is routinely obtained following surgery or upon disease progression. These patients regularly participate in tissue and biofluid donation for cancer studies, making them highly relevant for examining the ethical and practical aspects of biobanking. Additionally, they often face decisions related to privacy and the return of research results, which are central themes of our study.

Survey Design

The instrument was developed by the authors through a series of 116 preliminary stakeholder interviews and 11 focus groups with patients, physicians, scientists, institutional, and industry stakeholders between December 2021 and March 2022. To validate the survey and identify potential sources of error or ambiguity, survey questions were then pretested among several dozen professional and lay associates. These pre-testers included breast cancer patient advocates and leaders of local community groups, most of whom were breast cancer survivors who had completed initial treatment, as well as women's health professionals (breast cancer physicians, nurses, midwives, and allied clinical and research staff). The resulting feedback was used to refine the instrument's wording to maximize accessibility of language and understanding of the question content.

The survey consisted of three parts: patient demographics, patient clinical characteristics, and patient preferences about research using donated tumors/tissues. Specifically, the survey questions in the third part were explicitly designed to address the four research questions outlined in the Introduction: 1) patient notification and influence over how their donated biospecimens are used, 2) preferences about balancing privacy protections against receiving research results, 3) conditions under which patients would accept collaborations between nonprofit institutions and for-profit companies, and 4) preferences for how financial returns from commercially successful research should be distributed among donors. For research question 1 we asked general questions, such as whether patients are interested in learning what happened to their donated tissue, and also about specific scenarios, like the types of information they might learn. For research questions 2 and 3, we framed policy decisions as involving a balance between potentially conflicting objectives. Specifically, we inquired whether patients would be willing to make concessions on privacy in order to receive research results, and if they would prefer collaborations with for-profit companies if it accelerated the development of new treatments. For research question 4, we asked participants about their preferred approach for distributing financial returns among donors—specifically, whether returns should primarily benefit

individuals whose biospecimens directly led to breakthroughs, or if returns should be distributed more broadly among all donors.

Following best practices (Stantcheva 2023), participants were not obligated to answer all questions and had the option to skip any they chose. A $10 Amazon gift card was provided for participants. Participants had the option of participating in a 15-minute follow-up interview to review their responses for an additional $20; qualitative interview data will be reported in detail elsewhere.

Recruitment and Data Collection

Survey data were collected between 28 March and 14 June 2022. This study, "*Patient Views, Preferences and Engagement in Next-Generation Breast Cancer Biobank Research*," was approved by the University of Pittsburgh IRB (protocol 22010118) and the Johns Hopkins University IRB (protocol 00020507). Participants were recruited via flyers (see appendix Figure 1) posted in clinic waiting rooms (breast oncology, surgery, and other departments at the University of Pittsburgh hospital and satellite locations) and via local breast cancer advocacy networks. To be included in the research, participants self-verified current or former patient status at UPMC, English proficiency, and age ≥18 years old. The participant self-verification question indicated the patient was qualified to provide relevant insights. This is because they had undergone diagnosis and/or treatment in the setting of a clinical service line with an embedded biobanking platform, thus ensuring that their experiences were aligned with the study's focus on biobanking practices. Surveys were administered on patients' own mobile phones, computers, or study-provided tablets available in the clinic, and took approximately 15 minutes to complete.

Based on happenstance exposure to recruitment flyers (in contrast to a structured outreach strategy such as random selection), 109 participants were enrolled. It is important to acknowledge that our convenience sample approach may limit the generalizability of the results, as discussed below.

Analysis

Descriptive statistics were used to illustrate patient preferences. Socio-demographic factors associated with preferences were examined through multivariable Ordinary Least Squares regressions. Estimated coefficients represent percentage-point changes associated with unit changes in the regressors, and were reported with the associated standard errors and 95% statistical significance. All analyses were conducted in Stata version 17 software.

Table 1 shows the demographic and clinical characteristics of the 109 UPMC study participants. 5.9% of participants are in the 18-34 age group, 19.4% are 35-44, 32.8% between 45-59, and 26.9% are 60 or older. We note that racial and ethnic minorities are underrepresented in the sample. Looking at clinical characteristics, we observe that 77% of participants have been diagnosed with breast cancer; 23.8% are stage 1, 28.4% stage 2 or 3, and 21.1% are stage 4. The remainder of the participants were either undergoing diagnostic evaluation, clinical surveillance, or medical and/or surgical risk-reduction related to breast disease.

Results

We report our results on patient preferences in Tables 2 and 3. **Table 2** details patient preferences regarding consenting to research and their interest in the outcomes, as well as their views on notification and involvement in decision-making processes. **Table 3** outlines their views on profit sharing and collaboration within university-driven research, alongside preferences for revenue sharing in medical research advancements. Unless otherwise indicated, the percentages refer to the total 109 participants included in the survey. Tables 2 and 3 indicate the number of participants who were asked each question, the percentage of each answer, and also the percentage of non-response.

Patient Interest and Influence on Tissue/Tumor Research Use and Demand

In Panel A of Table 2, we report that about half of the participants surveyed (49.54%) reported having agreed to allow their breast tumor/tissue (from surgery or biopsies) to be used for research (question [1]). **Table S1** in the supplementary materials shows the correlates of the participants' likelihood of having agreed to donate their tissue/tumor for research, revealing that most socio-demographic and clinical characteristics are uncorrelated with this decision. In turn, 46.3% of participants who agreed to donate tissue/tumor stated that they wondered about what happened to the tumor/tissue they provided for research (question [2]). Moreover, 32% of those who never wondered about the fate of their tissue/tumor indicated they would want to know in a follow-up question (question [3]). Combining those who wondered what happened to the tumor/tissue and those who never wondered but declared they would like to know brings the total share of participants who donated their tissue/tumor expressing some interest in what happened to their donated tissue/tumor to 61%.

When certain benefits of knowing about tissue/tumor use were made salient (question [4)], expressed interest increased: 74% if genetic results could affect one's family's health, 68.5% if research results would affect their healthcare, 50% if they could learn details of the research, and 46% if tissues/tumor had unique or commercial value. The fraction of participants who said they were not interested ranged from 7.4% to 16.7%. The last row of Panel A reports the responses to question [5], which asked participants about their preference regarding being re-identified if research on their tumor/tissue potentially affects their healthcare or cancer treatment. This question highlights patients' choices when faced with the possibility that de-identification of research samples might prevent researchers from sharing results with patients or their doctors. Among participants who agreed to donate their tissue/tumor for research, 79.6 percent indicated they would want to receive the results, even if that would require re-identification. We posed the same question to participants who did not recall or were not offered the opportunity to donate their tissue/tumor, and 43.9% responded positively. In **Table S2** in the Supplementary Materials, we estimated multivariate linear probability models to explore the correlates of participants' (un)willingness to be re-identified to learn research results that could affect their health care or cancer treatment. Most socio-demographic and clinical characteristics are uncorrelated with the participants' propensity to be willing to be re-identified to receive the research results.

In Panel B of Table 2, we present results from questions that inquire about participants' perspectives regarding their involvement in decisions concerning the use of their tissue/tumor samples. Question [6] specifically addressed whether patients should be informed if their tumor/tissues are "in demand," meaning there is more than one prospective user per available biospecimen. This may be due to certain factors, such as pre-operative biopsy results or unique

biological features discovered during research. We find that 61.47% of participants expressed agreement with being informed about the demand for their specimens if known before surgery, if possible, while 58.72% indicated agreement if the demand was discovered later on. Furthermore, question [7] sought to gauge participants' preferences regarding their role in deciding who receives their tumor/tissues when researchers are competing for them. We report that 24.77% of patients agreed and an additional 20.18% strongly agreed that they should have a say in determining the allocation of their samples, underscoring the importance of patient engagement in research decision-making processes.

Patient preferences about collaboration between universities and for-profit pharmaceutical companies

We asked three questions to understand participants' preferences about universities collaborating with for-profit pharmaceutical companies and report the results in Panel A of Table 3. One question (question [7] in Table 3) asked whether nonprofit universities should maximize working with for-profit companies to speed the development of new treatments. Only 7.3% of participants said No. Meanwhile, 26.6% of participants said that nonprofit universities using tumors/tissues donated by patients should maximize working with for-profit companies to speed the development of new treatments. Another question (question [8] in Table 3) asked whether nonprofit universities that do research on tumors/tissues donated by patients should minimize the ability of companies to profit from patients' donated tumors/tissues. Here, 12.8% of participants said No. In contrast, 23.85% said that universities should minimize companies' ability to profit from patients' donated tumors/tissues. We note, however, that in both questions, the largest share of participants (46.79% and 44%, respectively) answered "Maybe", indicating that they did not have a strong opinion one way or another. In the third question shown in Panel A of Table 3 (question [9)], we asked participants to choose their preferred policy between minimizing the ability of companies to profit from patients' donated tumors/tissues, and maximizing working with for-profit companies to speed the development of new cancer treatments. When faced with this choice, 55.05% of participants stated they would prefer maximizing working with for-profit companies to speed the development of new cancer treatments.

Table S3 in the Supplementary Materials shows that most socio-economic and clinical characteristics are not significantly correlated with the participants' choice of preferred policy.

Patient preferences about receiving financial benefits from commercial discoveries using donated tissues/tumor

In a final set of questions, we asked whether the participants think that other parties involved (besides for-profit drug companies) should have a chance to obtain financial benefits. As indicated in Panel B of Table 3 (question [10), 42.58% of participants indicated that the patient whose tumor/tissues were used, or their loved ones, should have a chance to obtain financial benefits. Due to possible social desirability bias (e.g., a concern that the researchers might perceive someone as being greedy for stating that patients should obtain financial benefits), we consider this may be a lower bound on the true proportion of participants who believe that patients should participate in the financial benefits from discoveries obtained with their tumor/tissues.

Finally, we asked the participants to imagine a scenario in which profits from research products are shared with patients and asked them to indicate how they believe the profits should be shared. Specifically, we asked whether they thought the patient whose unique tumor/tissues

made the breakthrough possible should receive most of the money or if, instead, all patients who donated their tumors/tissues should share the money equally. As shown in Panel B of Table 3 (question [11]), 49.54% of participants reported that all patients who donated tumor/tissues should share in the profits from research, and 27.5% indicated that most money should go to the specific patient whose tissue was used that led to the breakthrough. The remaining participants had no opinion or did not answer.

Table S4 in the Supplementary Materials shows that no socio-demographic characteristics correlate significantly with the likelihood that participants indicated the patient whose unique tumor/tissue made the breakthrough possible should receive most of the money. Of the clinical characteristics, only two are statistically significantly correlated with the belief of interest: participants who were first diagnosed 5+ years ago were 62.8 percentage points more likely ($p<0.05$) and those who had surgery 5+ years ago were 46.9 percentage points less likely ($p<0.05$) to indicate that the specific patient should receive most of the financial reward.

Discussion

In our survey study of 109 breast cancer patients at the University of Pittsburgh Medical Center network in the United States, we found that they were generally interested in receiving follow-up information about their donated tissue samples. Interest increased when follow-up information included health-relevant information like genetic results. The participants were also interested in receiving follow-up information that was not clinically relevant. These findings are similar to those of other empirical studies; a recent review of patient preferences for returning results from biobank research found that, in all reviewed studies, over half of respondents were interested in receiving research results regardless of clinical significance (Vears et al 2021).

Current de-identification standards in the United States are governed by the "Common Rule" (2018), which places privacy protection at paramount importance in the balance of risks and benefits of research on biospecimens, particularly when specimens are procured as byproducts from clinically necessary interventions (i.e., no additional invasive procedures are performed for research purposes). These regulations often preclude the distribution of any beneficial follow-up to patients. Our findings show that patients in our survey population are willing to be re-identified if research finds clinically relevant information, suggesting that they are willing to relinquish some aspects of current privacy protections (e.g., prohibitions of recontact) under certain conditions. Today's norms of de-identification in United States biobanking make it difficult to accommodate patients' preferences for receiving research updates or results. Our findings show that these preferences extend to research in which patient identifiers are removed from biospecimen data. A re-examination of the terms of participation in such research may be prompted in light of emerging privacy-preserving technologies which help overcome tradeoffs between privacy, provenance, and utility of specimens/data (Racine 2021, Gross et al 2022).

Our research also sought to explore the conditions by which nonprofit healthcare institutions might collaborate with external, for-profit entities. While transacting with the private sector is recognized as a way to improve the value and sustainability of biobanks (Uzarski et al 2015, Hämäläinen et al 2019), surveys of the public have found mixed feelings on the acceptability of such partnerships, affecting willingness to participate in research and trust in research institutions. Critchley et al (2015) found a negative relationship between willingness to participate in biobanking when third parties were allowed access to biobank data. Critchley et al

(2021) found mixed levels of concern in response to different models of collaboration (e.g., funding partnerships, sharing/selling tissue). However, these studies demonstrating the public's disfavor of commercial uses of donated specimens generally consider commercialization as a singular issue, rather than framing it in context with alternatives and the need to balance possibly conflicting objectives. In our study, we framed public-private partnerships as a balance between potential outcomes of money-making by the private sector, along with the corresponding speedier translation of research and development of treatments. Our findings indicate that patients in our sample are generally supportive of such partnerships when considering that they are necessary for accelerating treatment development, and ultimately, the positive impact of research on health outcomes. However, they prefer transparency about the process, and about how profits are shared, with an emphasis on ensuring that public interests and patient contributions are recognized alongside corporate profits. These results are similar to a qualitative study by Spector-Bagdady et al. (2020), where cancer patients were found to be more comfortable with the commercialization of specimens and genetic data than clinicians, but still expressed concerns regarding how resulting profits would be used. If further confirmed in other contexts, this finding can inform the standards of collaboration with for-profit companies, suggesting that increased industry partnership may be a viable approach to improving biobank sustainability if such processes are done in a transparent manner.

Participants in our sample believe that researchers and nonprofit research institutions should receive a portion of profits made from research on donated tissues. However, over half of patients in our survey population also believe that biospecimen donors should share in profits derived from their contributions. Meanwhile, Allen et al (2018) found that, in a survey of 126 biospecimen donors, 95 (75%) participants stated they should not be paid for their participation in a tissue bank. While these results initially seem contradictory to our findings, they suggest there may be nuance in patients' perceptions of monetary compensation for donation in contrast to the sharing of profits reaped from biospecimen research. Our findings are significant, as they suggest potential policy disincentives for the introduction of greater transparency regarding ongoing commercialization activities.

While decentralized biobanking technologies may make the inclusion of patients feasible from a technical and regulatory standpoint, these innovations, on their own, may be insufficient for overcoming market forces relevant to the entrenched business models of the biomedical research enterprise. Conversely, the current model of leveraging de-identification of specimens may, in effect, confer a degree of privacy or freedom to operate, for researchers and non-profit research institutions, whose activities necessarily involve a mixture of basic science, commercial translation, and healthcare delivery. Further work is necessary to clarify patients' perceptions of profit-sharing and compensation in biospecimen research.

Limitations

This study has limitations. It is based on a small convenience sample of participants, which limits its statistical power. Due to the focus on a specific population—breast cancer patients within one academic, urban health system in the United States—the generalizability of the findings is also limited. The survey participants were mostly white women, reflecting the demographics of this region, disease, and research participation trends. Future studies involving a more diverse sample across various demographic and geographic settings would be needed to broaden the applicability of the findings from our survey. Furthermore, the scope of this study was specific to the American biobanking context, where one-time informed consent and de-

identification of samples are employed, which may not fully apply to clinical research settings where patients are more actively engaged.

Best Practices

Taken together, our findings may inform the development of new technologies that allow for individual discretion in biospecimen use, and lay the foundation for advancing institutional policies that promote more efficient commercial activities while calling for innovations in how profits are realized in service of the general public and specific donor/patient communities. This work is applicable to United States biobanking platforms and other research protocols that leverage a combination of one-time informed consent and subsequent de-identification of research samples and data. Therefore, our results may not apply to clinical research contexts, where patients are more actively engaged and where the prospect of clinical benefit is an overt possibility.

Policy decisions and technology implementation are intertwined and should be co-designed. While policies may make technological implementation feasible, and vice-versa, the development of new technologies requires significant investment.

Similarly, patient engagement need not end with the policymaking process. While patient preferences and incentives may differ from those of the institution or other stakeholder groups, including patients in the co-design of biobanking platforms and aligning incentives towards a common goal has the potential to improve the sustainability and scalability of biobanking via increased participation and trust.

Research Agenda

Critically, while the potential for novel technology solutions was part of the background rationale for this survey of patients, the possibilities for implementing transparency, return of results, and profit sharing through new technologies was not presented in the context of this baseline survey. In ongoing work, the research team is developing a new technology platform that implements decentralized biobanking as a novel framework for patient-centered biospecimen management. This framework is complemented by a set of blockchain-backed software solutions designed to implement transparency, enable engagement, and enforce accountability to patients regarding research on their de-identified biospecimens. Once such technology (or its possibility) is introduced, patient interest may shift. Details of our subsequent surveys, which assess patients' interests in using software applications to track their specimens, receive research results, and share in downstream profits, as well as prototype development and pilot implementations of decentralized biobanking applications, will be reported elsewhere.

We hypothesize that including patients in decision-making about investments in biobanking policies and infrastructure will impact the perceived trustworthiness of healthcare institutions, and possibly medicine and science more broadly. This hypothesis is rooted in prior literature that describes how patient engagement, including shared decision-making, transparent goals, and equitable resource distribution, is foundational to building trust (Wilkins 2018, Maria Chudyk et al 2024).

Accordingly, meaningful engagement and consideration of patients' preferences, in addition to systems designed to promote their inclusion as participants and beneficiaries, may help to repair distrust in both healthcare and biomedical research enterprises. For instance, Yadav et al (2023)

describe how biobanks can employ strategies including providing clarity on sample use and meeting with community leaders as mechanisms to rebuild trust and improve engagement with donors. Further direct engagement of patients on these issues can assess the impact of our proposed approach, as well as examine measurements of research participation, continuity of care, and other indicators of trust (Jaffe 2021, Ozawa and Sripad 2013). Continuous, longitudinal efforts to engage patients are critical due to the dynamic nature of trust-building between researchers and patients, where trust can be readily gained or lost (McDonald et al 2008). Finally, our findings can inspire further work to research and develop new technologies to enable and test new systems of governance and participation in biobank research (Gross et al 2023).

Educational Implications

Engaging patients offers a unique and underrepresented perspective in institutional decision-making and the development of research priorities (Bombard et al 2018). For instance, Forsythe et al. (2019) describe how patient engagement in research improved acceptability and alignment between patients' and clinicians' priorities. Understanding patient preferences and incentives can appropriately broaden the view of healthcare institutions and inform their underlying institutional values. While the findings from our survey emerge from a specific context, they illuminate wide gaps between patient preferences and existing institutional policy regarding transparency of research on donated biospecimens, commercialization of specimens or their derivatives, and distribution of profits from downstream discoveries. Our findings can also serve as a basis for discussion about what ought to be done about such gaps.

While this survey was done as empirical research, this method of engaging patients can be incorporated into institutional decision-making in other ways, such as quality improvement studies (Rolfe et al 2018). Patient engagement research such as this can spark conversation about the move from hypothetical research to more meaningful stakeholdership of patients in co-designing solutions to improve the sustainability and scalability of biobanking, with the aim of realizing precision medicine, institutional transparency, and structural justice for healthcare economies as standards-of-care.

Although it's important to interpret our findings with caution due to the relatively small sample size and limited representativeness, the results are in line with available evidence from other patient contexts. Nonetheless, more research is needed from varied samples of cancer and other types of patients to further elucidate our findings. Our study is based on the United States context and thus more closely applies to its specific regulatory environment. However, many of the issues we examined—such as the lack of routine patient information about how donated tissue is used, the absence of financial benefits for patients from discoveries, and the lack of patient input into what kind of research should be conducted with their tissue—are relevant in other regions, including Europe. For instance, Gille et al (2021) found that, across 69 biobanks in Europe and Canada, 29 (42%) did not provide any relevant, current, or accessible information on biobanking governance structures or procedures, reflecting a lack of transparency. Additional research should be conducted in European and other international contexts to broaden our understanding of patient preferences in biobanking and to explore how these preferences align with different regulatory frameworks.

Conclusion

From a sample of breast cancer patients from a major hospital in a major metropolitan area in the United States, our study reveals significant patient preferences regarding the use of their donated

tumor/tissue samples. A large majority of patients in our survey population want to know what happened to their donated tumor/tissue samples, especially if research results could influence their health care or their family members' health. Participants in this study are willing to be re-identified to learn research results that could affect their health. They are in favor of nonprofit universities partnering with for-profit companies if this leads to faster development of new therapies. They tend to be in favor of patients benefiting financially from research on their tissue but mostly believe that all patients who contributed samples to research should benefit, not just the person whose specific donation made the breakthrough possible.

These results offer novel and rich insight into patient preferences for certain scenarios for sustainable and scalable implementation of biobanking and can be used to inform institutional decision-making, systemic approaches to precision medicine, as well as the advancement of decentralized biobanking frameworks and technologies. Importantly, our results identify gaps between what patients want and the current standards of health systems, including norms of de-identification and collaboration with for-profit companies. As institutions seek to ensure sustainability of their biobanking infrastructure, incorporating patient feedback can help inform innovative policies and drive development of enabling platform technologies, especially in the face of balancing competing priorities (Finkelman et al. 2017), evolving cultural norms, and ethical imperatives.

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Table 1. Sample Demographics & Clinical Characteristics

Socio-demographic characteristics	n	% of sample (N = 109) (standard deviation in brackets)
18-34	6	5.89% (25.52)
35-44	21	19.36% (42.14)
45-59	36	32.83% (48.92)
60+	29	26.93% (46.75)
African American	7	6.73% (28.47)
White	69	63.13% (38.27)
Other	7	6.73% (28.47)
College+	50	46.29% (50.22)
Have children	42	38.72% (49.61)
Children live with them	8	7.58% (27.65)
Has siblings	50	45.45% (50.22)
Siblings live with them	2	1.68% (13.48)
Living with spouse or partner	57	52.18% (49.75)
Household income <=$34,999	16	14.31% (41.94)
Household income $35,000 - $69,999	15	13.47% (41.03)
Household income $70,000 - $99,999	12	10.94% (37.9)
Household income $100,000 - $149,999	14	12.63% (40.06)
Household income >=$150,000	14	12.63% (40.06)

Clinical characteristics	n	% of sample (N = 109) (standard deviation in brackets)
Diagnosed with breast cancer	84	77.06% (36.84)
Stage I	26	23.85% (46.5)
Stage II or III	31	28.44% (48.54)
Stage IV	23	21.10% (44.85)
Time first diagnosed <= 2 years	36	33.03% (49.78)
Time first diagnosed 3-5 years	22	20.18% (44.23)
Time first diagnosed > 5 years	26	23.85% (46.5)
Estrogen receptor negative	19	17.43% (43.39)
Progesterone receptor negative	27	24.77% (48.32)
Her2/neu receptor negative	50	45.87% (47.45)
"Triple negative"	15	13.76% (40.26)
Had breast cancer surgery	72	66.06% (31.62)
Surgery 5 years ago or more	23	21.10% (46.95)
Surgery 2-5 years ago	19	17.43% (44.38)
Surgery 6 mos-2 years ago	22	20.18% (46.38)

Surgery within past 6 months	8	7.34%	(31.64)
Had other breast cancer treatments	77	70.64%	(19.11)
Family members with breast cancer	55	50.46%	(49.8)
Family members with other cancer	60	55.05%	(48.82)
Has known cancer gene mutation	11	10.09%	(31.87)

Note: The sample comprises 109 survey respondents. The sum of certain subgroup totals may not equal 109 owing to instances of non-response on specific questions. Additionally, some respondents were only asked certain questions based on their answers to previous questions.

Table 2. Results: Patient Interest in research Outcomes and Decision-Making

Panel A - Patient Consent and Interest in Research Outcomes

		% of respondents (n in brackets)			
[1]	Did you agree to allow your breast tumor/tissue (from surgery or biopsies) to be used for research?	Yes	No	Not sure/Do not remember	Did not answer
		49.54% (54)	8.26% (9)	29.36% (32)	12.84% (14)
[2]	If answer to [1] = Yes: Have you ever wondered about what happened to tumor/tissue you provided for research?	Yes	No	Did not answer	
		46.30% (25)	46.30% (25)	7.41% (4)	
[3]	If answer to [2]=No: Are you interested in finding out what happened to tumor/tissue you provided for research?	Yes	No	Did not answer	
		32% (8)	64% (16)	4% (1)	
[4]	If answer to [1] = Yes: If possible, would you want to know what happened to your tumor/tissues? …	Yes	No	Neutral	Did not answer
	… If it could affect my health care	68.52% (37)	9.26% (5)	16.67% (9)	5.56% (3)
	… If there are genetic results that could affect my family's health	74.07% (40)	7.41% (4)	11.11% (6)	7.41% (4)
	… If my tissues or products made from my tissues are very unique or commercially valuable	46.30% (25)	16.67% (9)	29.63% (16)	7.41% (4)
	… To learn details of research that was done on my tumor/tissues	50.00% (27)	16.67% (9)	27.78% (15)	5.56% (3)
[5]	Research on tumor/tissues could be helpful to your health care or cancer treatment. Patient names are removed from research samples to protect patients' privacy (also called "de-identification") but this prevents researchers from returning results to patients or their doctors. If research on your tumor/tissue could affect your own health care or cancer treatment, would you prefer to ...	… Receive the results (requires re-identification)	…Remain anonymous (de-identified)	Did not answer	
	If answer to [1] = Yes	79.63% (43)	12.96% (7)	7.41% (4)	
	If answer to [1] = No	43.90% (18)	4.88% (2)	51.22% (21)	

Panel B - Patient Notification and Decision-Making in Tissue Research Demand

		% of respondents (n in brackets)					
[6]	Biopsy results and other information available before surgery can tell us if, which, and how many researchers might want to study that patient's tumor/tissue. Other times, unique features or value of a patient's tumor/tissues are iscovered during research, creating more "demand" for their samples in the future. Should patients be informed if their tumor/tissues are "in demand"?	Yes	No	Don't know / Not sure	Did not answer		
	Before surgery, if possible	61.47% (67)	9.17% (10)	11.93% (13)	17.43% (19)		
	If it is discovered later on	58.72% (64)	8.26% (9)	13.76% (15)	19.27% (21)		
[7]	How much do you agree or disagree with the following statement: If researchers are competing for a patient's tumor/tissues, that patient should help decide who gets them	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly Agree	Did not answer
		5.5 (6)	5.5 (6)	26.61 (29)	24.77 (27)	20.18 (22)	17.43% (19)

Note: The sample includes 109 survey respondents. Totals for some subgroups may not reach 109 due to non-responses to some questions. The table presents the questions exactly as they were phrased in the survey.

Table 3: Patient Preferences Regarding University Research Collaborations and Revenue Sharing

Panel A - Collaboration and Profit in University-Driven Research

		% of respondents (n in brackets)			
[7]	Do you think that non-profit Universities (like Pitt) who do research on tumors/tissues donated by patients, should maximize working with for-profit companies to speed development of new treatments?	Yes	No	Maybe	Did not answer
		26.61% (29)	7.34% (8)	46.79% (51)	19.27% (21)
[8]	Do you think that non-profit Universities (like Pitt) who do research on tumors/tissues donated by patients, should minimize the ability of companies to profit from patient's donated tumors/tissues?	Yes	No	Maybe	Did not answer
		23.85% (26)	12.84% (14)	44.04% (48)	19.27% (21)
[9]	Which of the following would be a better policy for non-profit universities (like Pitt) who do research on tumors/tissues donated by patients?	Maximize working with for-profit companies to speed development of new treatments.	Minimize the ability of companies to profit from patient's donated tumors/tissues.	Did not answer	
		55.05% (60)	22.94% (25)	22.02% (24)	

Panel B - Revenue Sharing in Medical Research Advancements

		% of respondents (n in brackets)			
[10]	Research on patients' tumors/tissues can lead to development of a new breast cancer treatment. Which of the parties involved (besides the drug company) should have a chance to make money? Select all that apply.	Yes			
	The patient whose tumor/tissues were used or their loved one	42.58% (46)			
	Other patients who contributed tumor/tissues for research	29.22% (32)			
	Cancer patient advocates or charities that supported the research	36.73% (40)			
	The patient's medical team who found, removed and treated the tumor	35.06% (38)			
	The researchers who worked on the scientific breakthrough	51.76% (56)			
	The insurance payor that paid for imaging and surgery	10.02% (11)			
	The university or laboratory where the research was performed	56.77% (62)			
[11]	All patient tumors/tissue are important for research, but some are very rare or unique. Sometimes one patient's tumor/tissue holds the key to unlocking a cure and they become especially useful for developing new commercial products. In your opinion, if profits from those products are shared with patients, how should the money be shared?	The patient whose unique tumor/tissues made the breakthrough possible should receive most of the money	All patients who donated their tumors/tissues should share the money equally	Other	Did not answer
		27.52% (30)	49.54% (54)	3.67% (4)	19.27% (21)

Note: The sample includes 109 survey respondents. Totals for some subgroups may not reach 109 due to non-responses to some questions. The table presents the questions exactly as they were phrased in the survey.

Appendix

Figure A1. Survey recruitment flier distributed within breast cancer clinics