Decentralized Biobanking for the Future of Precision Medicine

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Abstract

Background: Biobank privacy policies remove identifiers from donated specimens, siloing patients, discounting multi-modal data, and hindering precision medicine. Decentralized biobanking is a new paradigm that unlocks value by uniting patients, specimens, scientists and physicians in a blockchain-backed platform with robust incentives, governance and ethical oversight. Informed by a real-world pilot, this mixed-methods futures study explores how we advance decentralized biobanking from theory to practice.

Objective: 1) Define implementation strategy; 2) Synthesize pilot experiences into future vision; 3) Highlight implications and potential roadblocks.

Methods: We applied backcasting from 2021-2024 through ethnography, alignment exercises, surveys, interviews, site visits and futures workshops to map biospecimen supply chains and define principles for decentralized biobanking, utilizing a breast cancer biobank for prototyping and software development. A decentralized biobanking app was piloted to engage breast cancer biobank members in participatory visioning. Thematic analysis of app user experiences and pilot reflections revealed a technology-enabled future vision. We systematically analyzed the pilot event via a Futures Wheel, organizing participant quotes as first order effects, indirect effects, and anticipated implications.

Results: Backcasting unveiled a pathway for designing an initial application for patients to track their biospecimens within institutional databases. We defined the "rails, rules and tools" for a sustainable, effective, and structurally just Biomediverse. Pilot enrollment was robust, and concurrent biobank enrollment was increased. Qualitative themes revealed impact on dignity, recognition, understanding, belonging, ownership, and empowerment. A vision for the future emerged from user journeys: "From 'Lab Rat' to Research Partner," vividly depicted as a path transitioning from sterile graveyard to flourishing community garden. Primary themes were matched to first order effects, indirect effects and future implications, culminating in gratitude and unity, network effects reinforced by reciprocity, as well as compensation and precision medicine, suggesting next steps.

Conclusions: Reconnecting patients with their donated biospecimens via decentralized biobanking applications unlocks value for patients and aligns incentives across the Biomediverse. We illuminate the future person-centered biomedical data economy and put forward the goal of enabling all U.S. biospecimen donors with decentralized biobanking by 2030.

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Keywords: Biobanking; Biospecimens; Decentralized Biobanking; Precision Medicine; Blockchain Technology; Non-fungible tokens; NFTs; patient empowerment; futures methods; backcasting; Futures Wheel; visioning; participatory research; learning health system

Total word count: 5,800

Introduction:

Biobanks collect biospecimens, like tissue and blood leftover from clinical procedures, for biomedical research. To protect privacy, patient names are removed before specimens are accessed by scientists. Consequently, patients rarely learn about personal contributions to science, and scientists are prohibited or deterred from communication with donors under terms of use.[1] However, eliminating patients' connections to their specimens leads to ambiguous ownership, misaligned incentives, and missed opportunities for precision medicine. Manual, ad hoc collection and siloed storage encourage hoarding and limit collaboration between public and private sectors.[2-4]. Under this model, patients do not benefit from research on their specimens, even if it could save their life, and most donated specimens are frozen or discarded.

Decentralized biobanking is a new paradigm for biomedical research and precision medicine that centers patients as principals in a personalized health data architecture. Synthesizing bioethics, biobanking and blockchain, our approach implements user-friendly software applications and blockchain-backed infrastructure to unlock value while meeting user needs across healthcare and biomedical research contexts. Decentralized biobanking, abbreviated as “de-bi,” emerges from the democratic ethos, transparency, tokenization and trust affordances of blockchain technology. Our digital twin ecosystem represents entities as non-fungible tokens (NFTs), immutable, provably unique cryptographic assets recorded on the blockchain. A decentralized biobanking ecosystem is designed to be privacy-friendly, flexible, composable with legacy systems and incentive-aligning with embedded potential for global impact. [5]

We apply backcasting to advance decentralized biobanking, seeking a path forward that overcomes tension between utility, value and efficiency of biospecimens while upholding donors' rights to respect, privacy, and benefit sharing.[6,7] This mixed-methods futures study identifies first steps for reducing de-bi to practice by working backwards from our proposed ideal for a biomedical metaverse, or “Biomediverse.” We define initial implementation strategy, informed by technical and qualitative experiences from the first real-world de-bi pilot [8,9]. We review participant quotes to assess our proposed approach, inspired by participatory visioning and aided by a Futures Wheel to identify insights, barriers and next steps.

2.0 Methods:

2.1 The Vision: When people think of biospecimens, they often picture a tissue or blood sample that is primarily used by clinicians for disease diagnosis and treatment guidance. There is no question that these samples are indeed integral for informing patient care, however, biospecimens are so much more than a snapshot in time. When linked to other datasets that encompass patient demographics, clinical outcomes, or even lifestyle factors, biospecimens allow researchers to construct disease patterns and longitudinal timelines that may have remained otherwise undiscovered. Moreover, linkage to other types of data such as genomics, proteomics, and pharmacogenomics datasets will significantly expand the overall understanding of the interplay between different biological and environmental factors that affect disease initiation and progression.

Figure 1. Status Quo vs. Our Vision for Decentralized Biobanking for Personalized Data Networks

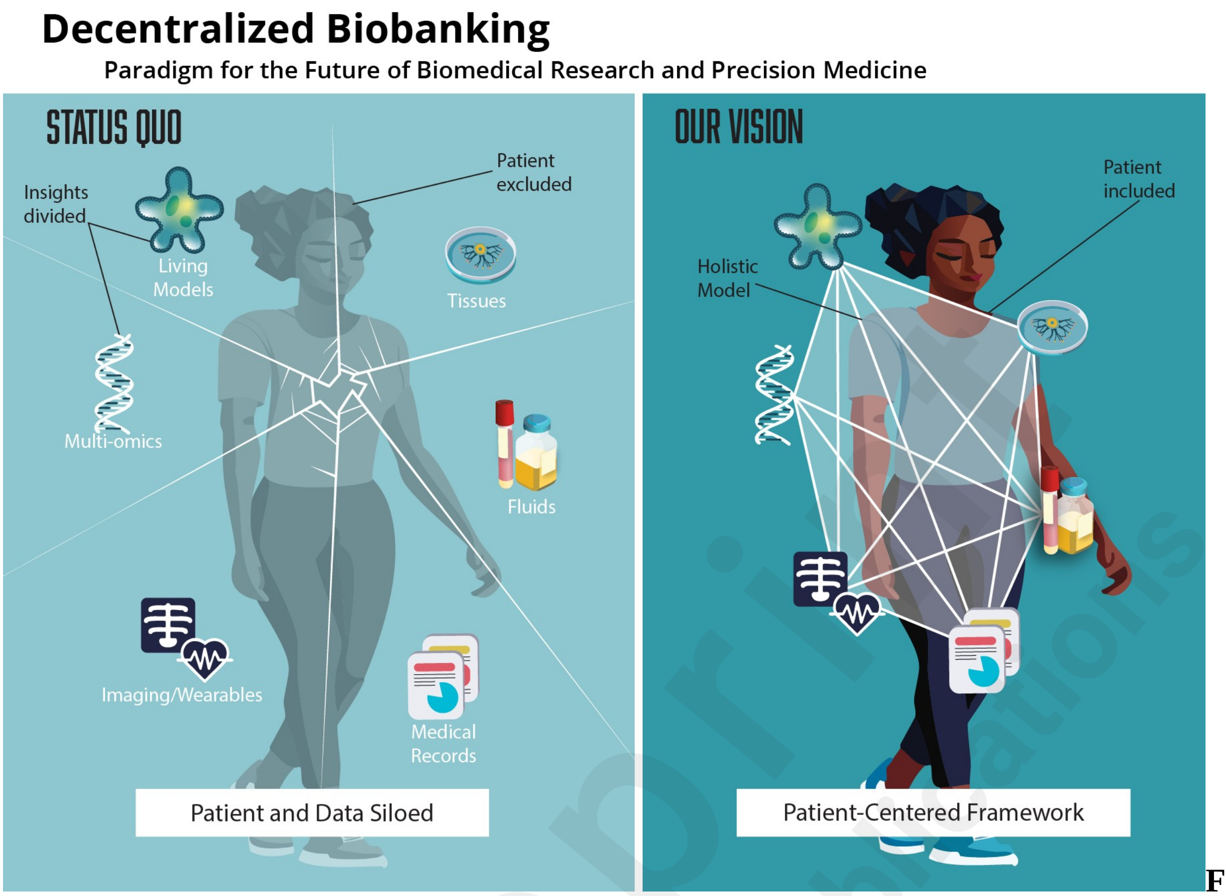

Figure 1. Left: Current ethical frameworks and health systems silo patients from data derived from their biospecimens; Right: Vision for a patient-centered data framework that interconnects individuals with their biospecimen-derived data, unlocking opportunities to collaborate with a diverse ecosystem of physicians and scientists. See detailed data typologies in **Appendix Table 1**.

In the status quo, biospecimens are siloed from the patient and from one another, hindering harmonization of multimodal data, contributing to a fragmented ecosystem where learning and translational impact are impaired. However, continuity of care for patients requires continuity of care for their data, including all physical and digital biosamples. The promise of precision medicine, achievable in the era of generative AI, demands health data architectures that center patients rather than institutions. In **Figure 1** (left), the patient is greyed out, behind the glass, showing how she is not the principal concern regarding her biological data. **Figure 1** (right) demonstrates our vision, where a decentralized overlay network forges an interconnected digital twin framework that supports peer-to-peer connections between all nodes. The patient is illuminated, indicating recognition and involvement in the biomedical data economy. She is the central figure, around whose interests data, stakeholders, and incentives are aligned in the sustainable future state.

Over the past several decades, clinical outcomes in patients suffering from cancer have significantly improved. Without question, a key contributor to such enhanced overall survival and therapeutic efficacy is the availability of biospecimens for translational research. As detailed in this study, however, patients – who are the most important stakeholders in the healthcare ecosystem – are often prohibited from tracking and learning the fate of their biospecimens within the research lifecycle.

Moreover, scientists are currently restricted in their ability to convey comprehensive, potentially life-changing biological findings to patients and their healthcare providers. We aim to mend this fragmented connection between cancer patients and scientists, thus, removing considerable barriers to precision medicine and the development of tailored interventions. We utilize backcasting to identify practical steps to move from the status quo to our future vision.

2.2 Futures Methodology: Backcasting was essential for guiding our strategy and systems design, especially given the potential for dead ends to be built upon current biobank structures. Our approach sought to identify where incremental changes are insufficient and long-term investments in technological solutions are required.[9] Primary activities were conducted 2021-2024, incorporating mixed-methods research, community engagement, participatory design, prototyping, app development, pilot testing, and feasibility studies to advance a comprehensive roadmap (**Table 1**).[10] Data synthesis was complemented by participatory visioning and a Futures Wheel facilitated pilot analysis.

Table 1. Overview of Research Methodology & Timeline

2021	2022	2023	2024
• Problem framing • Ideation • Visioning • Stakeholder meetings and preliminary feedback • Use case selection • Initial prototype	• Alignment exercises with key stakeholders types • Futures Workshop • Site visits • Surveys x2 • Stakeholder interviews • Design Workshops • More prototypes	• Develop & refine apps • Real-world pilot for breast cancer biobank w/ survey • Cognitive walkthroughs & app onboarding • Stakeholder Presentations • Participatory visioning & community engagement • More interviews	• Feasibility analysis: Technical, Operational, Regulatory & Economic • Data synthesis for Futures Wheel • Dev new technologies • Real-world pilot for translational research w/ survey • Comprehensive roadmap & policy framework

2.3 Baseline Assessment: We mapped biospecimen supply chains and incentives through ethnography with patients, physicians, biobankers, scientists, IRB members, institutional leadership, and industry professionals, including a series of alignment exercises and futures design workshops for key stakeholder groups (e.g., **Appendix Table 2**). [11] Site visits, interviews, and surveys enriched our perspective. We defined unique problems and value propositions with a focus on viable "low hanging fruit" with near-term utility for the biomedical industry. Design strategy was translated into strong product concepts primed to overcome barriers and launch the revolution.

2.4 Real-World Biobank Setting: Initial research and development occurred in the setting of one of the world's largest dedicated breast cancer biosample collections (STUDY19060196-- Breast Disease Research Repository (BDRR): Tissue and Bodily Fluid and Medical Information Acquisition Protocol). From 1995-2023, roughly 11,000 patients consented to donate, from which 4,000 unique donors had contributed approximately 61,000 specimens. Nearly 10% of the inventory had been distributed for research and 90% remained in long-term frozen storage. The BDRR is a hub-andspoke model biobank nested within an institutional biobanking platform at a U.S. NCI Comprehensive Cancer Center, and features a flagship living biobank of approximately 300 patient-derived breast cancer organoids. Organoids are 3D tumor models grown in the lab, a culturally, clinically and commercially significant biospecimen use case exemplifying the urgency and potential impact of decentralized biobanking. [12]

2.5 Defining the Pathway: We plotted the range of possible initial interventions as a function of potential impact and relative effort to identify the first step for digitally bridging bench and bedside. Initial technical development focused on allowing patients to track biosample donations, an essential step for involvement throughout the research lifecycle. Our approach renders biospecimen information from biobank databases in a patient-friendly interface, leveraging existing asset-based transactions, data infrastructures and public familiarity with asset tracking applications, e.g. 89.3% (25/28) of patients in our design survey utilize online banking.

We hypothesized that such a technology could provide personalized feedback while remaining compliant with de-identification, compatible with established workflows and, composable with ongoing collection protocols. Successfully demonstrating these features would yield a scalable mechanism for providing passive transparency for donors, without requiring active participation from physicians, biobanks or scientists. Hence, specimen tracking may minimize friction for onboarding while simultaneously building trust and generating opportunities to unlock value for dense atomic networks of patients and scientists with shared assets and interests.[13] Milestones were outlined in **Box 1**.

Box 1. Key Milestones for Patient-Centered Biospecimen Tracking

1. Design patient-friendly biosample tracking app
2. Develop and integrate app with institutional biobank
3. Deploy app for real-world biobank pilot use case
4. Demonstrate potential impact and value of patient engagement

2.6 Blockchain-Backed Biospecimen Tracking: We designed and validated decentralized biobanking “de-bi” application interfaces to display readily available biospecimen data and biobank activities in an accessible and privacy-preserving manner.[11,14] After a series of prototypes, we developed and deployed a de-bi mobile app for Android and iOS. Privacy-by-design was applied to maintain compliance with established de-identification protocols.[9,15-17] The app utilized NFTs as non-transferrable “soulbound” tokens, signifying donors’ immutable relationship to their specimens, with token-claiming representing assertion of the right to ongoing transparency and simulating token-gated access to personal bioassets. The app was tested and refined with potential users from October 2022-January 2023 (QRC #3958).

2.6 Pilot Study: Biobank members were recruited Feb 16 – Apr 30, 2023 for the sample tracking app pilot (IRB #22020035). One thousand eighty participants enrolled, nearly 10% of eligible biobank members (930/9750). Approximately 600 app invites were distributed and 405 downloaded the app on their personal device and completed onboarding during the 10-week pilot. Collectively, 272 pilot participants were reconnected with 3,904 specimens, with a mean of 14.5 specimens per donor (range 1-84), of which 1.4 (range 0-9) were distributed for research. Of note, 261 biobank enrollments occurred during pilot recruitment in 2023 (2/16-5/4), a 65% increase over the 158 observed during the same period in 2022 (p<.001). No participants withdrew from the biobank during or for one year following the pilot (p<.001). Pilot methods, data collection, regulatory considerations, technical and operational feasibility are reported in-depth elsewhere. See **Appendix Table 3** for demographics.

2.7 Data Sources: Qualitative research observations, comprising representative quotes from participatory futures exercises, design workshops, pilot correspondence, cognitive walkthroughs and immersive engagement were thematically coded to explore key values and perspectives regarding decentralized biobanking. Verbatim text was coded initially by 4 independent team members who reviewed writing exercises and video transcripts, supplemented by direct quotes from virtual and in-person app onboarding, biobanking educational sessions and community events.

2.8 Participatory Visioning: Mixed-methods research, community engagement and pilot testing, served as rich case study for participatory visioning. Over several years of deep hanging out, we witnessed firsthand as participants considered future prospects of decentralized biobanking, rediscovered their specimens via the de-bi app, and grappled with present implementation vs. future potential. Pilot participants engaged in futures-focused exercises, e.g., letter writing, imagining alternative futures, and exploring how de-bi might impact relationships with their own body, biomedical research, and the healing process. [18] A vision of research transformation coalesced from app users' lived experiences, developed via thematic synthesis of participant quotes and quantitative data in context.[19] Narrative synthesis was graphically depicted and refined iteratively through a series of reflections. Representative quotes were mapped onto the emergent vision of an evolutionary model.

2.9 Futures Wheel: The pilot was selected as the key event and placed at the center of a Futures Wheel. Direct effects were mapped from representative quotes from primary themes of participant feedback during app engagement and onboarding. Indirect effects were visualized by dissecting higher-order lived experiences, as described by participants. Finally, potential implications of decentralized biobanking, as articulated by pilot participants, were organized as offshoots of the indirect effects, suggesting an array of potential positive and negative feedback loops. [20]

3.0 Results

3.1 Decentralized Biobanking Framework: The goal is a sustainable, collaborative Biomediverse where all people, assets and protocols are maximally aligned in synchronized healthcare and research systems (**Figure 2**). This requires engaging patients as principals with enduring interests in their specimens to disintermediate supply chains, facilitate linkage of siloed data and accelerate discovery and delivery of precision medicine. However, moving towards the ideal future state is challenged by de-identification, and procedures like broad informed consent, which engender misalignment of incentives by disconnecting individuals from downstream research activities and products. In the resulting biobank ecosystem, rational self-interest among remaining stakeholders leads to suboptimal outcomes for society: waste, inefficiency, and missed opportunities to realize the potential of biospecimens for generation of collective health and wealth.

Figure 2. Biomedical Metaverse "Biomediverse" Schematic: Decentralized Biobanking Ecosystem of People, Studies, and Samples

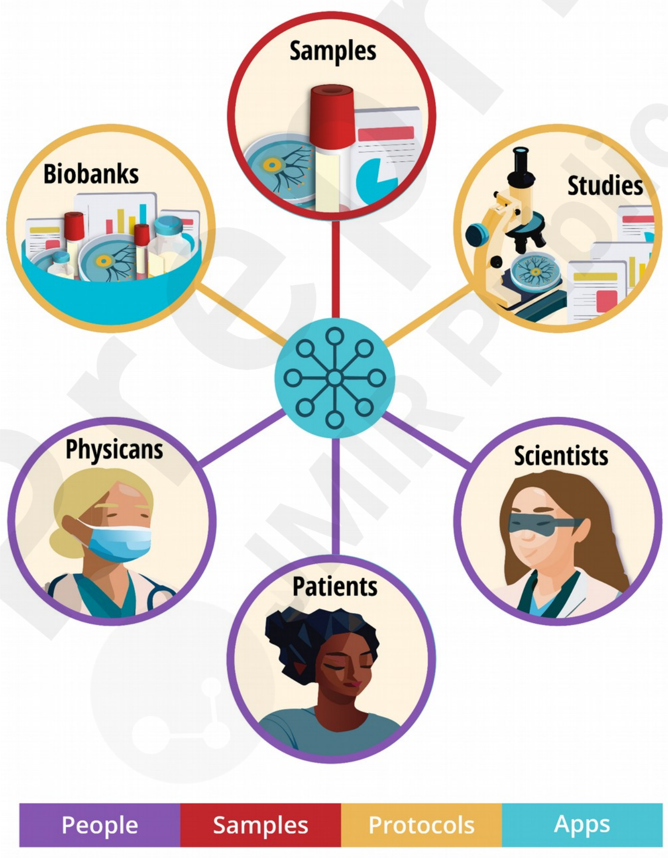

Figure 2 demonstrates the Non-Fungible Token Digital Twin Ecosystem in which all people, samples and protocols are united via a decentralized biobanking framework that integrates seamlessly with respective data resources and activities.

3.2 Components & Core Elements: Decentralized biobanking presents the 'rails, rules and tools,' of a structurally just Biomediverse wherein all people, protocols and biological products are connected via symmetrical digital and moral infrastructure (**Table 2**). Our NFT digital twin ecosystem combines human-centered architecture, an ethically-governed marketplace, and composable software applications that synergistically advance the universal mission of individual health and collective human flourishing.

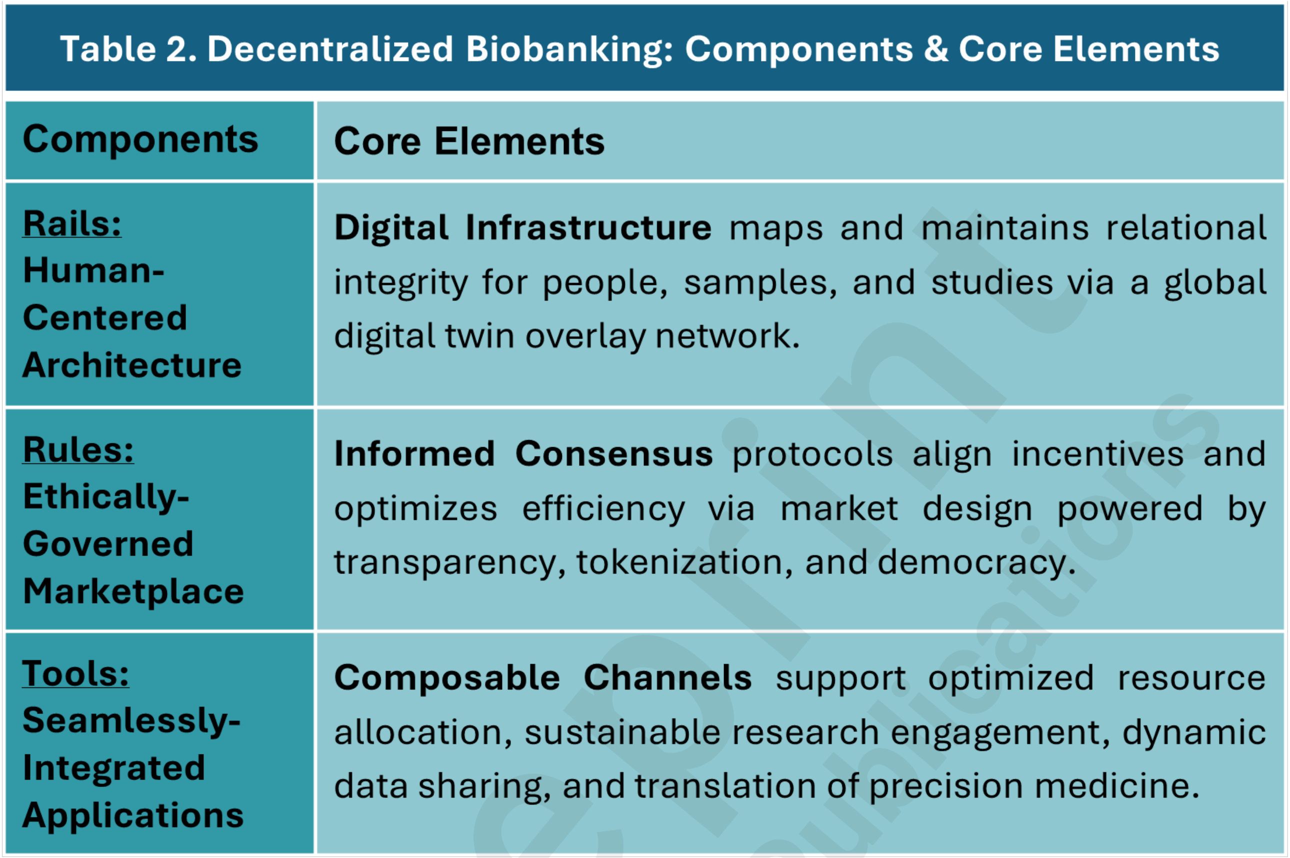

Table 2. Decentralized Biobanking: Components & Core Elements

Components	Core Elements
Rails: **Human-Centered Architecture**	**Digital Infrastructure** maps and maintains relational integrity for people, samples, and studies via a global digital twin overlay network.
Rules: **Ethically-Governed Marketplace**	**Informed Consensus** protocols align incentives and optimizes efficiency via market design powered by transparency, tokenization, and democracy.
Tools: **Seamlessly-Integrated Applications**	**Composable Channels** support optimized resource allocation, sustainable research engagement, dynamic data sharing, and translation of precision medicine.

Our framework provides transparent digital infrastructure and collaborative governance solutions to close gaps in current health systems that waste most biological assets and permit missed opportunities to save lives. Decentralized biobanking implements distributed shared ledgers, tokenization, and privacy-friendly innovations in a stepwise fashion, progressively unlocking cumulative layers of value from existing silos.[21] These technologies may help restore trust through advancing a shared state of truth in which the rights and interests of individuals and enterprises may be maximally aligned.[22]

3.3 App Features: Four contexts and corresponding features were introduced, providing personal-level and community-level specimen tracking in an accessible manner (**Figure 3**).[23] We illustrate (1) **Biobank**, where donors could learn about biobanking and track the entire collection; (2) **Biowallet**, where donors could view and track the status of personal specimens; (3) **Profile**, where donors demonstrate the ability to share clinical data, annotate specimens and set research preferences, and (4) **Lab**, where donors could follow research activities enabled by their specimens and engage with personalized communities. Detailed app user journeys and NFT components are reported elsewhere.[24]

Figure 3. Decentralized Biobanking Platform for Biospecimen Donors: Technology Solution Overview and User Journey Map

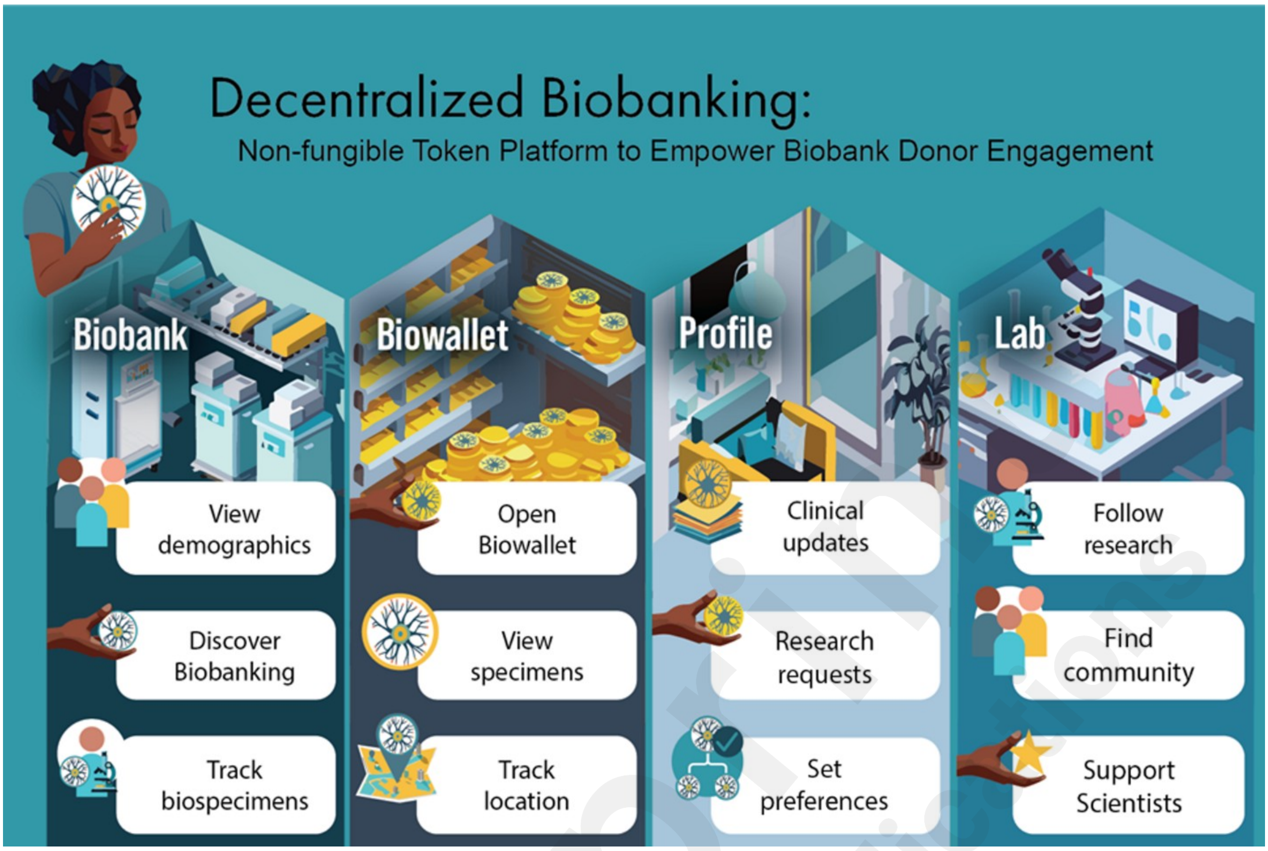

Figure 3 illustrates four key contexts and available features within the decentralized biobanking "de-bi" app piloted for breast cancer biobank donors, demonstrating the potential to build upon and unlock value for existing biobanks in a stepwise manner.

3.4 Participatory Visioning: From Scavenger Graveyard to Garden of Empowerment

3.4.1 Thematic Overview: Rich visions were constructed from in-depth narratives (n=10), drawing primarily from six transcribed videos and six writing samples. These were thematically reinforced by written feedback from design workshops, direct quotes from over 100 unsolicited emails from the pilot, and immersive community engagement. Overall, participants were enthusiastic about the chance to track their biospecimens, seeing the platform as a source of personal meaning and deepened knowledge of the research process. Qualitative feedback underscored the transformative potential of decentralized biobanking, illuminating direct effects on **dignity, recognition, understanding, belonging, ownership, and empowerment** (**Appendix Table 4**).

Participatory engagement yielded a future vision in which digital infrastructure embeds transparency, unlocks value and fosters collaboration. The direct effects of the app, as expressed by pilot participants, were organized in a cumulative process. The overarching narrative was synthesized into vivid imagery, representing transition from a sterile graveyard of biospecimen donation, to a vibrant community garden for research collaboration (**Figure 4**). Representative quotes were mapped along the route, illustrating the transformation, summarized by one participant: *"I feel I am moving from the role of 'lab rat' to research partner."*

Figure 4. "From Lab Rat to Research Partner:" Decentralized Biobanking Transformation

Figure 4 key themes and representative quotes from participatory visioning with the de-bi pilot participants are illustrated above, demonstrating evolution from the sterile biospecimen donation graveyard of today to a vibrant community-driven garden.

3.4.2 Narrative Vision: Direct Effects of de-bi Pilot

One participant describes a baseline for biobanking in which the effectiveness of prospective informed consent is limited by the primacy of concurrent clinical considerations:

> *I was originally diagnosed with breast cancer, I underwent surgery and samples were taken, and I know I signed a consent right before a procedure occurred, but I never thought about 'what's happening with the stuff that people are carrying away from me?' I thought of it as, 'This information is going to be used for my medical team to make decisions about this treatment or that treatment.' But I hadn't thought about 'What else happens with my cells?'*

Another participant wrote about how the process of consenting for biosample donation was synonymous with loss of self-sovereignty she experienced during the respective radical mastectomy. *"The very moment I gave my consent…my connection to my own tissue was about to come to an abrupt end in the cold sterility of the surgical suite. Whatever fruit those cells might yield in the lab was destined to be… remote to me."* By contrast, she experienced renewed **dignity** through re-connection to her biospecimens, explaining: *"One might say that de-bi has provided for the re-membering of my bodily integrity…From radical mastectomy to radical restoration."*[25] The deeply personal nature of breast cancer surgery underscored participants' interest in following their tissues, addressing unmet need for **recognition,** as illustrated by the statement, *"I want to be recognized, the acknowledgement of like, yes, that's my sample."*

The pilot platform advanced **understanding**, as in, "*with this special app…I can essentially peek in* *and see what's happening.*" Participants experienced an awakening of awareness about biobanking, exemplified by a participant's vision: *"Our cells…are sitting somewhere, like Sleeping Beauty, waiting to be kissed...But…instead of a kiss, I get an app…"* The user experience of the de-bi application also engendered **belonging**. For example, "*You're not out there alone. You can go onto this app and see that there are other people who have this kind of tumor or diagnosis."*

Participants made comments like, *"I can't wait to see what's being done with my samples!" [original emphasis and punctuation]*. By tracking corporal contributions to science, we portended the sense of "*restored **ownership***" of the body, evoking a digital repatriation of de-humanized byproducts [26] Finally, participants indicated **empowerment**, emphasized by one who said: *"With this app, everybody becomes a colleague…. Because they know, I've got these cells, I've got these samples, and it's my cells, it's me, who's actually pushing the science forward…"* Reflecting, she noted, *"It's at those moments when you realize that this is a collaborative effort, right? We, as patients, are giving as good as we're getting."* [27]

3.5 Futures Wheel: Building on direct effects, we mapped indirect effects of the pilot onto a Futures Wheel, with themes of **appreciation, advocacy, community, legacy, solace** and **provenance**. Future implications for **gratitude, unity, network, reciprocity, compensation,** and **translation,** further emerged, illustrating potential feedback loops that may accelerate or stymie adoption (**Figure 5**). [28]

3.5.1 Indirect Effects: Pilot participants emphasized **appreciation** for research, attributing their survival to contributions of prior donors and scientific achievements. For example, "*Some might say that I'm lucky…but I'm very aware it's not just luck. My successful treatment with Herceptin was the product of many years of medical research. And that research was made possible by women like you and like me who donated their tissue samples."* Participants illustrated how seeing the impact of personal contributions would promote a positive feedback loop via **advocacy**: "*If patients understand the value of research, then they can be the messengers. They can be the advocates for all kinds of research, not just research that affects them individually…"*

The pilot reinforced a sense of **community**, especially through the virtual lab environment, where participants were able to track their specimens alongside those from individuals with a similar location, study, diagnosis or investigator. Explaining the value of our approach, one said, "*it may not help me right now, but it might help my cancer sisters*." Intimacy was deepened through the interpersonal exchanges of three-dimensional human matter, highlighting a profound sense of personal and collective identity tied to biological research contributions. **Solace** emerged as a silver-lining, illustrated by one who wrote, *"it was no small comfort to know that these cells, toxic to me, might prove beneficial to others.*"

Tracking samples was especially important for some facing metastatic disease, who may be reassured, achieving immortality through seeing their "*cells are still there to contribute to scientific discoveries,*" even after death. A lasting **legacy** was forged for individuals and their loved ones, whereby ongoing impact of research donations seemed to meaningfully extend lifespan. The widow of one donor emailed, "*It fills my heart that she is still helping others through this donation…it would be a gift to let [our children] know their mom is still helping others from the cross she had to bear."*

Digital representations of biospecimens were viewed as concrete cellular subcomponents arising from the embodied self, laden with psychosocial, emotional, and clinical significance. Motifs of materiality and **provenance** were central, powerfully articulated through one participant's comparison of herself to the narrative of Henrietta Lacks: “*There was no connection between Ms. Lacks and all the treatments that have ensued. But this way, it's as though I get to step into Henrietta Lacks’ body, and walk into a lab somewhere, and put my hand on the shoulder of somebody in a white coat, bent over a dish, looking at my cells, trying to figure something out…and I can see what’s happening.”*

Figure 5. Participant-Driven Futures Wheel: Direct Effects, Indirect Effects and Future Implications of de-bi

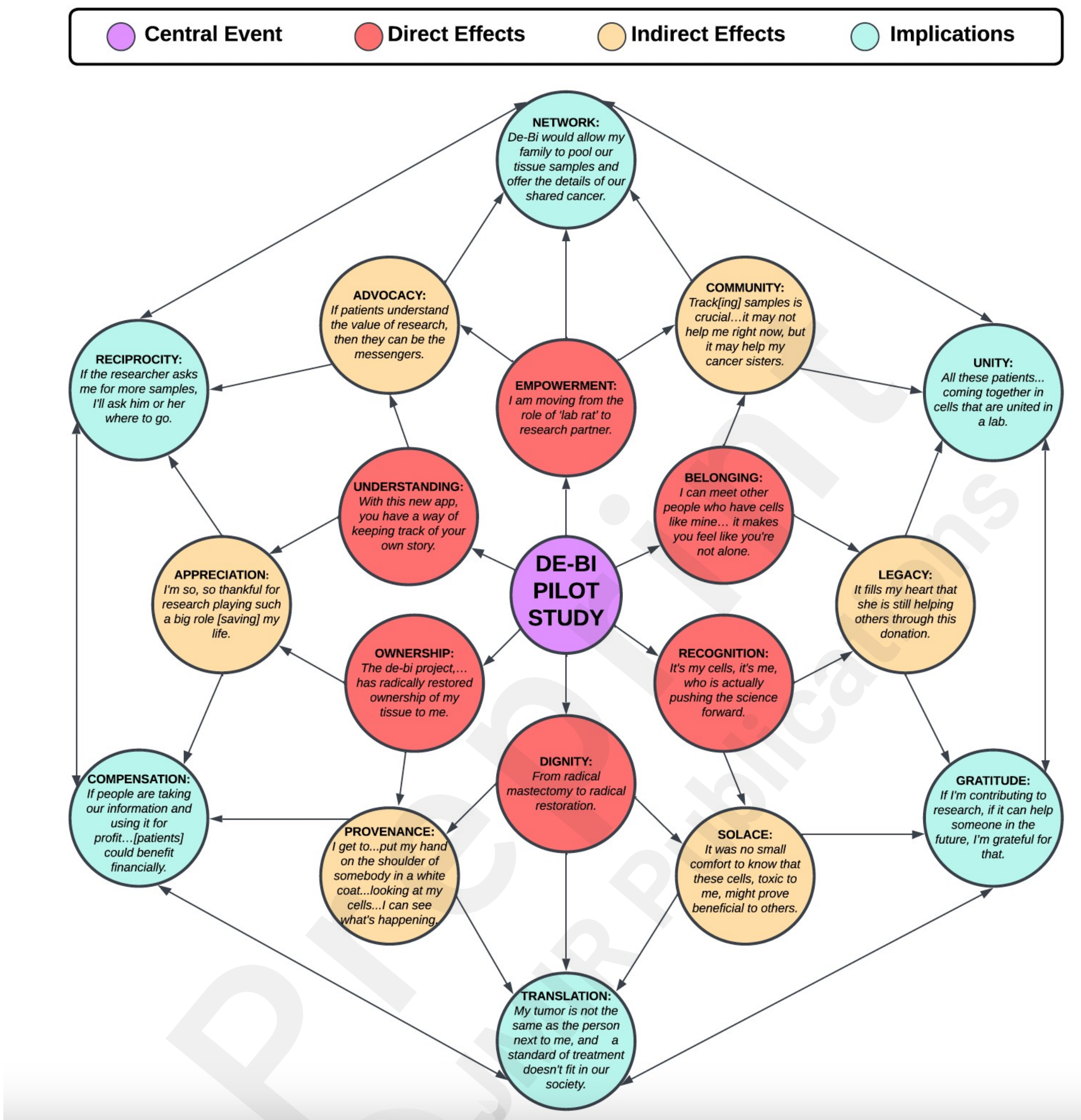

Figure 5 maps pilot participant quotes onto a Futures Wheel, demonstrating the direct effects of the de-bi pilot experience, ensuing indirect effects and future implications.

3.5.2 Implications:

The app fosters **gratitude** by making users feel valued and acknowledged, and allowing them to express the same for fellow donors and scientists**.** For example, one noted, “*I am so, so thankful for the role of research in [saving] my life*,” and another stated, “*If I'm contributing to any kind of research, if it can help someone else in the future, I’m grateful for that.*” The donation of tumor tissue was salient, as the very object that harmed the donor was converted into a tool for benefiting others.

Participants internalized recognition of their role in research as a way of being part of something larger than themselves, finding **unity** in the global effort to "*outsmart cancer.*" For example, one notes, "*Rarely does science change with one patient. But when you have ten, and ten to the second power, ten to the third power… all coming together in cells that are united in a lab, that's when science changes.*" Another stated, "*We are all in this together. The de-bi project is an important step toward maximizing research benefits for everybody.*" One explained, "*the app would be very beneficial …because what I have is rare, so there might be a…chance that I could find somebody else out there who is…going through the same thing.*" The potential to augment patients' support systems by combining the social value of togetherness with opportunities for personalized learning was emphasized.[25]

The application illuminated a hidden **network** of connections within the biobanking ecosystem, enabling future potential for linkage of similar specimens, donors and data across institutions. Participants recognized the potential for digital infrastructures to build trust and promote collaboration. For example, one wrote, "*My family is at high risk for breast cancer yet negative for all currently known breast cancer genes. De-Bi would allow my family to pool our tissue samples and offer the history and details of our shared cancer.*" She highlights how decentralized biobanking may help answer outstanding questions, unlocking "*potential discovery of a new breast cancer gene by studying our tissues.*"

Others highlighted how feedback loops may spur **reciprocity,** supporting serial specimen donations, as in, "*If the researcher asks me for more samples, I'll ask him or her where to go and I will be there.*" Participants noted how the app might help drive utilization of frozen specimens, with both personal and pro-social benefits in mind. For example, "*As more and more people learn about the de-bi app, you as a patient [can use the platform] to let researchers know that your tissue is out there for them to use in research*."[25] This sense of agency may inspire participants to contribute more actively, and suggests potential to amplify recruitment, retention and engagement. For some, feedback about their personal contributions is its own reward, as in, "*I am more interested in being able to see how my specimens are used in research. If they can help at least one person, it will do more good for me than money possibly could*."

By contrast, several participants envisioned how de-bi might allow patients to share profits derived from their specimens, with supply chain transparency enabling new economic models for just **compensation**. Patients were most interested in accessing commercial gains as redress for the financial toxicity of cancer, especially among young adults whose careers may have been cut short by their disease. Meanwhile, some were concerned about "*how to prevent misuse and financial gains by others,*" highlighting how perceived lack of respect for patient sovereignty may erode trust. Transparency regarding commercialization represents a potential source of negative feedback that may challenge institutional adoption or credibility among users, poignantly captured by one participant who said, "*it pisses me off that they make so much money off of us, but I don't want their money– I just want a cure, I just want to be here for my kids.*"

Ultimately, participants recognized the potential for de-bi to facilitate personalized medicine, informed by firsthand knowledge that "*everybody's cancer is different…and what works for one person might not work for another…*" and inspired by how bridging bench and bedside "*will enable the correct treatment to be used.*" One participant in her 20s was attuned to the need for direct **translation**, stating, "*I know that my future [survival] depends on both advocacy and research and* *this app has the potential to be a remarkable tool in my journey."* Similarly, participants discussed how de-bi might democratize precision medicine, as in, *"Everybody should be able to have this research done because my tumor is not the same as the person next to me…there are multiple drugs, multiple tumors, so why not find out what works?"*

4.0 Discussion

Biobanking frameworks and information systems are not designed to keep biospecimen donors informed, return of results is the exception, not the rule, and most biobanks are underutilized and insolvent. Decentralized biobanking reimagines the future of biomedical research and precision medicine with a person-centered health data framework that aligns incentives for patients, physicians and scientists as collaborators in a Biomediverse that maximizes utility, value and respect for biological assets. This futures study applies backcasting to define core, non-overlapping principles of decentralized biobanking and mobilizes theory into practice through design and deployment of a real-world pilot.[9] We demonstrate a targeted technology solution for re-connecting donors to their biospecimens, enabling personalized feedback without compromising established privacy-preserving mechanisms. [30]

We engaged institutional leadership, regulatory specialists, and biobank stakeholders to identify specimen tracking as the essential first step for systemic change. Doing so allowed us to zero-in on the "low hanging fruit" to advance a technically straightforward and cost-effective solution, with potential to deliver outsized benefits while minimally burdening existing cultures, workflows and infrastructure.[10] Participatory visioning demonstrated how a digital "*seat at the table*" for donors may catalyze a paradigm shift from "*lab rats*" to citizen scientists. [31] The Futures Wheel illustrates how de-bi technology may represent an open platform with positive feedback loops and network effects, creating an avenue for future precision medicine and profit-sharing.

4.1 Pilot Reflections

Nearly 10% of biobank members signed up to track their specimens in just two months, and there was a 65% increase in biobank enrollment during the pilot vs. the same time in the year prior. Personalized specimen tracking positioned the application as a groundbreaking tool for research collaboration with implications for intergenerational health. For some, donated biospecimens exhibited a 'phantom limb' phenomenon: gone, but never truly forgotten.[32] Compared to blood and urine samples, breast tissues exuded special meaning, possibly in relation to their structural role in reproduction and identity-formation. Mapping direct and indirect effects revealed profound positive feedback loops that may enhance donor participation and data sharing through empowerment and reciprocity.

Our approach fosters belonging by connecting user communities with related tissues, diagnoses or research investments, promoting sustained engagement by unlocking authentic relationships.[33-35] We also leveraged nonfungible tokens to facilitate implementation of patient rights and inclusion in the biomedical data economy, all while maintaining compliance with de-identification standards.[36] By allowing individuals to share data and vote on research proposals, we suggested potential to accelerate research via patient-driven integration of clinical data. As participants engaged in annotating their specimens and following donations to specific protocols, they sensed implications for how their preferences and interests might direct specimen allocations in the future.

However, with enhanced engagement comes the need to define rights and guardrails to support patients and institutions, particularly regarding data ownership, control and commercialization. If respect for donors' agency does not meet expectations, negative feedback loops may emerge, potentially undermining trust and jeopardizing institutional reputations.[37] Disappointed participants may withdraw, prompting scientists to be fearful of repercussions from earnest disclosures regarding research limitations, funding, monetization or other sensitive topics.[38] Thus, decentralized biobanking may reveal ethical dilemmas for the research enterprise, potentially sparking skepticism or resistance to adopting transparency. Careful design and communications are essential for patients and professionals alike, and must provide clarity about current capabilities and governance of the platform, in addition to future potential that our approach may spark.

Decentralized biobanking may generate an inclusion-advocacy flywheel. By providing a window into individual and group-level biobank activity, donors can be included in the research process, in turn promoting further involvement, and creating new opportunities for longitudinal collaboration.[39] Analogous to quadratic funding, which amplifies individual participation by prioritizing broad-based support over concentrated financial influence, decentralized biobanking has potential to amplify patient voices and distribute power across the research ecosystem. [40] Thus, specimen tracking suggests potential for early return on investment (ROI) via promoting research recruitment, retention, and engagement efforts. This flexible platform opens multiple possible benefits for the research enterprise, wherein 80% of clinical trials fail to meet enrollment targets, community engagement is a funding criterion, and linkage of serial specimens and multimodal data are essential to data quality and scientific impact. [41]

Biospecimens contain numerous layers of key information specific to a patient’s tumor, but so many of these potentially game-changing biological clues remain sequestered within the research laboratories of academic institutions. By facilitating sample tracking and data sharing between scientists, patients, and their care teams, we will remove the veil that has separated these indispensable stakeholders for far too long. Subsequently, patients will be able to unlock the value of their own biospecimens in an unprecedented way. This network of transparency has the power to transform patient outcomes through the following: 1) discovery of novel cancer mutations and molecular subtypes, 2) accurate prediction of patient response to treatment, 3) identification of new drug targets within a specific cancer and, perhaps most importantly, 4) allowing patients to play a powerful and active role in the eventual eradication of cancer for future generations.

4.2 Limitations

Decentralized biobanking recognizes the potential for biospecimen research to inform the same individual’s healthcare. One key limitation relates to use of non-human subjects research regulations for biobanking, wherein research proceeds without IRB oversight, explicitly eschewing intervention or interaction with living individuals.[42] The underlying presumption is that there is no duty to return results, as the results are not considered clinically actionable. Our work highlights how this widespread practice results in missed opportunities to fulfill the duty to rescue individuals based on learning from specimens collected during the provision of medical care. In this setting, regulatory considerations, e.g., surrounding non-CLIA laboratories, presented early barriers for direct translation of bench research, notwithstanding conceptual appeal and growing sense of moral injury among physicians and scientists. Similarly, anticipation of downstream payor constraints were raised, highlighting potential challenges for justifying coverage of clinical testing or interventions via specimen studies classified as “research-use-only.”

Likewise, while the de-bi app showed the status of specimens regarding whether they were *collected* or *distributed* for research, we were not permitted to reveal specifically *which* scientists were using the specimens, *how* they were used or *results* thereof. Hence, our technical approach for providing personalized biospecimen feedback focused on providing donors with access to the hub of the biobank database, but did not extend to the research database spokes. Thus, further research and development are needed to determine *how* best to establish linkages between donors and biomedical research, *which* raw data to display for transparency and optimizing access to *results*, while minimizing stress, therapeutic misconception, confusion and other potential risks.

Importantly, the pilot disproportionately engaged white women with breast cancer in a single region, insufficiently representing the vast array of patients, populations and conditions that may be impacted by decentralized biobanking. Additionally, the piloted app was tailored for biospecimen donors, thus further research and development must address perspectives of physicians, scientists and other stakeholders. Future pilots are needed to validate findings with the most underserved populations and the most complex and impactful scientific research modalities (such as patient-derived organoids) to advance a robust and sustainable model that can accommodate critical edge cases.

Providing transparency regarding biobank assets via representing personal biospecimens in a biowallet interface empowers patients' sense of restored ownership. Accordingly, vested interests of biopharma companies, health systems and academic institutions which profit from no-strings-attached biosample donations represent the foremost barrier to implementing decentralized biobanking. Yet, for our use case, as with most biobanks, 80-90% of specimens remain in long-term frozen storage, creating financial burdens and undermining progress for the same entities [43,44]. By enabling donors to track their specimens and share benefits from research contributions, a decentralized biobanking platform may address market failure by clarifying ownership and engaging stakeholders with 'rails, rules and tools' engineered to foster collaboration and effective resource utilization.

4.3 Futures Directions

We believe that the time has come for patients to be empowered to track their personal contributions to biomedical research: an inevitable consequence of normalization of mobile computing and internet access for U.S. residents. This approach fits within contemporary calls for transparency to restore trust in healthcare systems, and is thematically consistent with Information Un-Blocking mandates under the 21st Century Cures Act.[45] To this end, our first major goal is to advance the decentralized biobanking platform to empower every patient in the U.S. to track the samples they donate for research by 2030.

Our proposed person-centered infrastructure will enable a framework for returning benefits to patients, yet will require further innovations and policies to ensure safety and quality. Once biospecimen research may be unlocked to deliver precision medicine solutions, we will be uniquely positioned to harness newfound alignment of stakeholders in an ethically governed biospecimen marketplace. The platform also allows donors to enrich biosample annotation, aid in linkage of siloed datasets, and improve resource utilization via decentralized governance mechanisms. Both nonfungible and fungible tokens may prove useful for promoting efficient collaboration, sharing specimens via decentralized exchange, and providing essential transparency and auditability affordances of blockchain systems. Elsewhere, we discuss ongoing research and development of decentralized biobanking solutions that benefit from blockchain functionality while minimizing friction for user onboarding and integration with legacy technologies.

Engaging patients as stakeholders is key to developing ethical marketplace solutions to enhance social value, institutional trustworthiness, and economic sustainability. Further research is needed to define new models for ethical monetization of biospecimens in partnership with patients and communities. Market validation will require institutional stakeholders to appreciate how they will benefit from democratizing biobank assets. The ability to unlock collaborations between nonprofit biobanks and industry partnerships is a key value proposition—now more than ever in the current research funding environment. [46]

Designing our system to optimize resource utilization and ensure efficient, effective and just distribution of benefits is necessary to promote the flourishing of precision medicine as a standard-of-care.[47] Continuous monitoring and iteration will be required as the model for patient-centered biobanking emerges, is hardened and developed to accommodate the wide range of potential use cases. Also, there may exist initial hesitancy in the general population about joining new health/research technologies, particularly ones with a seemingly complex financial component. This issue highlights the importance of an initial implementation focused on specimen transparency, as an opportunity for education and further research on market designs in tandem with scale-up in order to optimize acceptability and assuage emergent concerns.

Engaging patients through decentralized biobanking not only enhances transparency and empowerment regarding their biospecimens but may also foster a greater willingness to share additional behavioral data—such as that obtained from wearable devices. Integrating such real-time, patient-generated health metrics with clinical and biospecimen data could offer clinicians and researchers a more comprehensive view of health trajectories, thereby informing more personalized treatment strategies. Moreover, as the platform evolves, its capacity to host biobanks and patient cohorts from multiple institutions could pave the way for large-scale research studies. In this expanded ecosystem, patients would become full partners, contributing rich, multidimensional data that would otherwise be difficult to amass, ultimately transforming the landscape of precision medicine.

4.4 Conclusion

Reconnecting patients with their specimens represents a powerful first step for decentralized biobanking that balances ethical obligations, legal precedents and marketplace demands. Implementing transparency for biospecimen donors regarding their specimens is compatible with current biobank workflows, compliant with de-identification and necessary for overcoming lethal information asymmetries between bench and bedside. Enabling patients to track their specimens with a decentralized biobanking app represents “low hanging fruit” with potential for early ROI by aligning intrinsic incentives and promoting reciprocal research participation, relational integrity and provenance. Ongoing research seeks to optimize engagement, support seamless return of results, and validate ethical market designs for the decentralized biobanking ecosystem. Reuniting patients and donated specimens may evolve into a holistic digital twin framework, creating a foundation for the future of precision medicine, by building upon existing biobanks while inviting a sustainable, person-centered Biomediverse.

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Appendix

Appendix Table 1. Details for Health Data Asset Taxonomy

- Living models, like organoids and PDX
- Tissues, including fresh, frozen or preserved solid biopsies or surgical samples
- Fluids, like blood, urine or sweat
- Multi-omics like genome, proteome or microbiome
- Imaging and wearables, from MRIs or smart-devices like watches, glucose monitors or biometric sensors
- Medical records, including doctors notes, labs, pharmacy and claims data

Appendix Table 2. Futures Design Strategy Workshop Activities (April 2022)

Day 1

Set Long Term Goal & List Questions
Ask the Experts
  - § Learning Health Systems
  - § Biospecimen Property Law
  - § Return of Results for Research
  - § Behavioral Economics/Market Design for Biospecimens

Make a Map
Pick a Target

Day 2

Lightning Demos:
  - Blockchain, Distributed Systems, NFTs
  - Ethics and Decentralized Biobanking
  - Organoids and Precision Medicine

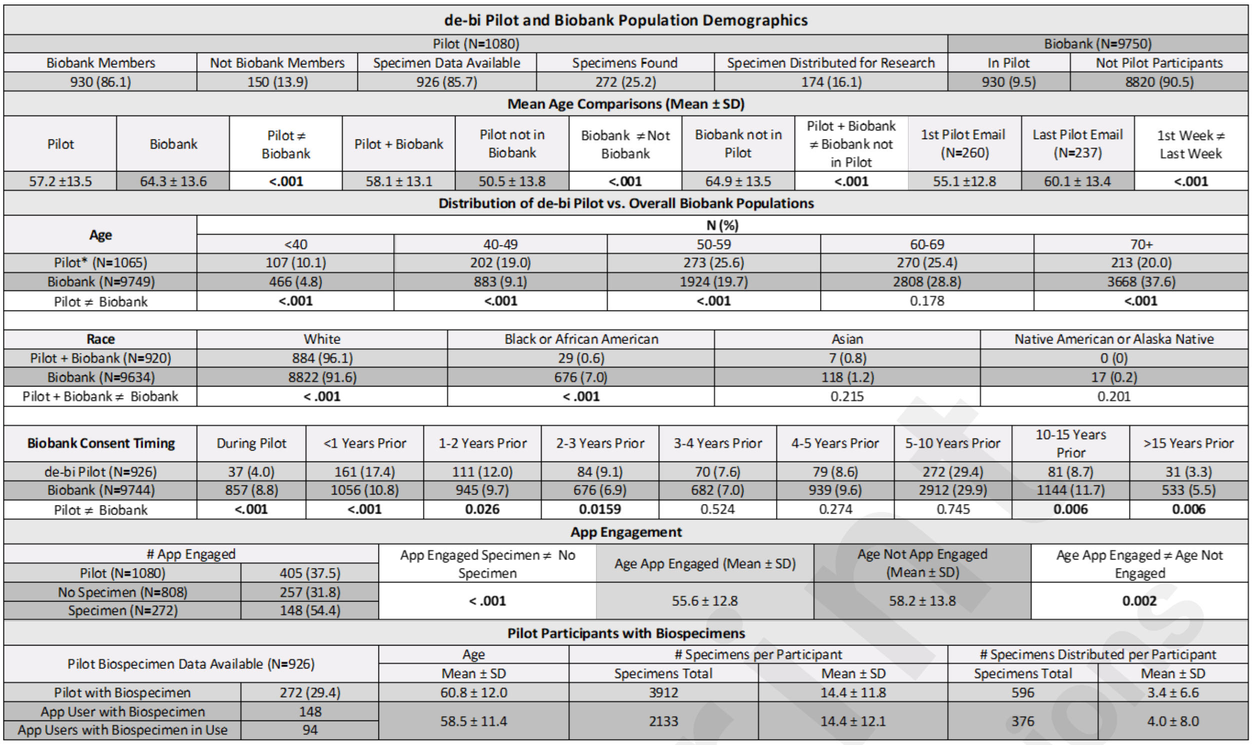
§ Cybersecurity issues in blockchain/NFTs
§ On integrating patient advocates into research activities
§ Product development theory and process
§ Trust networks, cooperation and social influence in online market design
Organoid Lab and Biobank Tour
Divide or Swarm
Four Step Sketch

Day 3

Concept Gallery & Dot Vote (Heatmap)
  - Speed Critique
  - Straw Poll & Supervote
  - Separate Supervote Winners

Rumble or All-in-One
Storyboard / Roadmap

Appendix Table 3. de-bi Pilot Population Demographics



de-bi Pilot and Biobank Population Demographics

Pilot (N=1080)					Biobank (N=9750)	
Biobank Members	Not Biobank Members	Specimen Data Available	Specimens Found	Specimen Distributed for Research	In Pilot	Not Pilot Participants
930 (86.1)	150 (13.9)	926 (85.7)	272 (25.2)	174 (16.1)	930 (9.5)	8820 (90.5)

Mean Age Comparisons (Mean ± SD)

Pilot	Biobank	Pilot ≠ Biobank	Pilot + Biobank	Pilot not in Biobank	Biobank ≠ Not Biobank	Biobank not in Pilot	Pilot + Biobank ≠ Biobank not in Pilot	1st Pilot Email (N=260)	Last Pilot Email (N=237)	1st Week ≠ Last Week
57.2 ±13.5	64.3 ± 13.6	**<.001**	58.1 ± 13.1	50.5 ± 13.8	**<.001**	64.9 ± 13.5	**<.001**	55.1 ±12.8	60.1 ± 13.4	**<.001**

Distribution of de-bi Pilot vs. Overall Biobank Populations

Age	N (%)				
	<40	40-49	50-59	60-69	70+
Pilot* (N=1065)	107 (10.1)	202 (19.0)	273 (25.6)	270 (25.4)	213 (20.0)
Biobank (N=9749)	466 (4.8)	883 (9.1)	1924 (19.7)	2808 (28.8)	3668 (37.6)
Pilot ≠ Biobank	**<.001**	**<.001**	**<.001**	0.178	**<.001**

Race	White	Black or African American	Asian	Native American or Alaska Native
Pilot + Biobank (N=920)	884 (96.1)	29 (0.6)	7 (0.8)	0 (0)
Biobank (N=9634)	8822 (91.6)	676 (7.0)	118 (1.2)	17 (0.2)
Pilot + Biobank ≠ Biobank	**< .001**	**< .001**	0.215	0.201

Biobank Consent Timing	During Pilot	<1 Years Prior	1-2 Years Prior	2-3 Years Prior	3-4 Years Prior	4-5 Years Prior	5-10 Years Prior	10-15 Years Prior	>15 Years Prior
de-bi Pilot (N=926)	37 (4.0)	161 (17.4)	111 (12.0)	84 (9.1)	70 (7.6)	79 (8.6)	272 (29.4)	81 (8.7)	31 (3.3)
Biobank (N=9744)	857 (8.8)	1056 (10.8)	945 (9.7)	676 (6.9)	682 (7.0)	939 (9.6)	2912 (29.9)	1144 (11.7)	533 (5.5)
Pilot ≠ Biobank	**<.001**	**<.001**	**0.026**	**0.0159**	0.524	0.274	0.745	**0.006**	**0.006**

App Engagement

# App Engaged		App Engaged Specimen ≠ No Specimen	Age App Engaged (Mean ± SD)	Age Not App Engaged (Mean ± SD)	Age App Engaged ≠ Age Not Engaged
Pilot (N=1080)	405 (37.5)				
No Specimen (N=808)	257 (31.8)	**< .001**	55.6 ± 12.8	58.2 ± 13.8	**0.002**
Specimen (N=272)	148 (54.4)				

Pilot Participants with Biospecimens

Pilot Biospecimen Data Available (N=926)		Age	# Specimens per Participant		# Specimens Distributed per Participant	
		Mean ± SD	Specimens Total	Mean ± SD	Specimens Total	Mean ± SD
Pilot with Biospecimen	272 (29.4)	60.8 ± 12.0	3912	14.4 ± 11.8	596	3.4 ± 6.6
App User with Biospecimen	148	58.5 ± 11.4	2133	14.4 ± 12.1	376	4.0 ± 8.0
App Users with Biospecimen in Use	94					

[1] (Not equal to)
± (Plus or minus)
SD (Standard Deviation)
< (Less than)
> (Greater than)

*Population demographic proportions were calculated from data with parameters of interest known. Not all entries in Breast Disease Research Repository (BDRR), or biobank, and de-bi Pilot datasets had age data available. Only de-bi pilot participants who were biobank members had race and date of initial biobank consent known. Not all de-bi study participants had the opportunity to test the app. Approximately 200 additional participants received app download invites, but had either not downloaded the app or not created an account before the pilot was completed. Biospecimen data was only available for BDRR members, and some individuals may not have matched to their respective biospecimens due participant typos on the electronic de-bi enrollment consent form and/or institutional database errors that were discovered during data analysis. Of note, approximately one third of BDRR members had contributed specimens to the breast cancer biobank as of the conclusion of the de-bi pilot.

Appendix Table 4. Participatory Visioning: Direct Effects of de-bi Pilot

THEME	REPRESENTATIVE QUOTE	VISIONING

Empowerment	*With this app, everybody becomes a colleague. … it's my cells, it's me, who's actually pushing the science forward… And it's at those moments when you realize that this is a collaborative effort… So, we as patients are giving as good as we're getting. And those are the magical moments for me.*	Participants envisioned a future where research is no longer a top-down process but a true collaboration, where patients are recognized as equal partners contributing to scientific progress. They imagined a system where their personal stake in research is acknowledged, and their involvement has real impact—transforming the research experience into one of mutual respect and shared purpose.
Belonging	*Just knowing that you're not out there alone. You can go onto this app and see that there are other people who have this kind of tumor or diagnoses.*	Participants imagined a future where the app fosters a sense of community and connection—where individuals facing similar diagnoses can find one another, share experiences, and feel less isolated. They envisioned a supportive space that reminds them they are part of a larger collective, united by shared journeys and contributions to research.
Recognition	*I want to be recognized, the acknowledgment of like, yes, that's my sample.*	Participants envisioned a research system that acknowledges their vital contributions—where their biospecimens are not anonymous or forgotten, but personally recognized as part of advancing science. They hoped for a future where donating a sample comes with the dignity of being seen and valued as an individual, not just a source of data.
Dignity	*The contribution felt disembodied: pun both intended and fitting … the very moment I gave my consent - was that my connection to my own tissue was about to come to an abrupt end in the cold sterility of the surgical suite. Whatever fruit those cells might yield in the lab was destined to be as remote to me as were any youthful illusions of eternal health and invincibility.*	Participants envisioned a future where donating tissue is not a disembodied act but one that retains a sense of personal meaning and connection. They hoped for a system that preserves the dignity of the donor—where individuals remain linked to the future fruits of their contribution and are recognized as ongoing partners in the scientific journey, rather than being forgotten once the tissue is collected.
Ownership	*Cancer might have compromised my sense of bodily integrity…but the de-bi project…de-bi has radically restored ownership of my tissue to me.*	Participants envisioned a future where, despite illness, they could reclaim a sense of ownership over their bodies and contributions to science. Through the app, they imagined restoring control and authority over their own biospecimens—transforming donation from an act of surrender into an act of agency and empowerment.
Understanding	*I thought, our cells and other samples are sitting somewhere. Sort of like Sleeping Beauty, waiting to be kissed. That sounds a little bit passive, because we have to wait for the prince to come in. But in this case, the prince is wearing a white coat…. And instead of a kiss, I get an app. And that app actually allows me to see what where my samples are. They're in freezers all over Pittsburgh and the environment around Pittsburgh just waiting for somebody to have an idea to test some new, treatment or approach to identify something about these cells of mine and the other women who are on this journey.*	Participants envisioned a future where they no longer feel in the dark about what happens to their samples, but instead have clear insight into their journey and potential. They imagined a system that replaces passive waiting with active understanding—where an app connects them to the ongoing life of their samples and the research possibilities they hold, making the scientific process visible and relatable.

Appendix Table 5. Futures Wheel: Direct & Indirect Effects, and Implications of de-bi Pilot

DIRECT EFFECTS		
Empowerment	*As a participant, I feel I am moving from the role of 'lab rat' to research partner.*	By providing a platform for viewing individual and group-level biospecimen activity, donors were included in the research process with a dedicated digital "seat at the table," setting the stage for further involvement and engagement.
Belonging	*I can meet other people who have cells like mine… in a two-dimensional space, on an app on my phone...It makes you feel like you're not alone, because we're not.*	The shared biological features of participant tissues and lived experiences of breast cancer treatment and its sequelae binds patients together in a profound, grounding, eternal way that transcends their individual lifetimes.
Recognition	*With this app, everybody becomes a colleague. … it's my cells, it's me, who's actually pushing the science forward…And it's at those moments when you realize that this is a collaborative effort… So, we as patients are giving as good as we're getting. And those are the magical moments for me.*	Participants highlighted the value of de-bi as a means of sharing knowledge gained from research on donated biospecimens that could inform intergenerational health, enabling continued positive impact from beyond the grave.

Dignity	*One might say that de-bi has provided for the remembering of my bodily integrity…From radical mastectomy to radical restoration.*	The ability to help other breast cancer patients through the tangible gift of one's diseased tissues was a significant motivator: the same material object that harmed the individual patient became a tool for healing others.
Ownership	*"I can't wait to see what's being done with my samples!*	Patients were interested in tracking the journey of their personal specimens, sanctified substrates for scientific research with which they had an innate connection and a sense of ownership, reified by visualizing their specimens in the app.
Understanding	*You can be the victim or be the advocate. With this new app, it's nice to have your own way of knowing what's going on with your disease and keep track of your own story. As we look forward to the day when cancer can be managed as a chronic illness and not a death sentence, I'm happy to participate in anything that advances research and patient rights.*	Patients recognized the potential for de-bi to facilitate access to data from studying their own specimens, as well as those with similar disease morphology, which they saw as potentially relevant for informing clinical decisions.
	INDIRECT EFFECTS	
Community	*Helping track anyone's samples at this point is going to be crucial to the advancement of medicine… it may not help me right now, but it may help my cancer sisters.*	By creating transparent systems for biospecimen tracking, donors felt a sense of shared purpose and collective benefit, recognizing that their participation could contribute to broader medical advances that support others in the community, even if not directly benefiting themselves.
Legacy	*I'm writing you on behalf of my late wife… It fills my heart that she is still helping others through this donation… We have two grown children… and it would be a gift to let them know their mom is still helping others from the cross she had to bear.*	Biospecimen donation was seen as a way to create a lasting impact beyond an individual's life, offering families a sense of meaning and continuity. Through ongoing contributions to research, donors and their loved ones found comfort in knowing their experiences could benefit future generations.
Solace	*I was especially invested in the opportunity to contribute to breast cancer research. And, given the particularly personal and radical nature of the surgery, it was no small comfort to know that these cells, toxic to me, might prove beneficial to others.*	The opportunity to contribute to research provided emotional comfort and a sense of purpose, transforming a difficult and deeply personal experience into something meaningful. Donors found reassurance in knowing that their challenging journey could potentially help others.
Provenance	*There was no connection between Ms. Lacks and all the treatments that have ensued. But this way, it's as though I get to step into Henrietta Lacks body, and walk into a lab somewhere, and put my hand on the shoulder of somebody in a white coat, bent over a dish, looking at my cells, trying to figure something out. And so I have my hand on their shoulder, and I can watch, and I can see what's happening.*	By being able to trace the journey of their biospecimens, donors felt a personal connection to the research process, transforming an otherwise invisible contribution into a shared experience. This sense of presence and acknowledgment addressed historical gaps in recognizing the origins and humanity behind research materials.
Appreciation	*I just embrace every single day that I have. And I'm so, so thankful for research playing such a big role in my life and having a really strong impact.*	Participants expressed deep gratitude for the role research has played in their lives, recognizing how scientific advancements shaped their care and outcomes. This appreciation fueled a desire to give back to research efforts that could help others in similar situations.
Advocacy	*If patients understand the value of research, then they can be the messengers. They can be the advocates for research… not just research that affects them individually.*	Donors saw themselves as potential advocates, using their experiences to promote the importance of research. By understanding the broader value of scientific work, they felt empowered to encourage others to participate and support research beyond their personal circumstances.
	IMPLICATIONS	
Network	*My family is at high risk for breast cancer yet negative for all currently known breast cancer genes. De-Bi would allow my family to pool our tissue samples and offer the history and details of our shared cancer. While samples exist from all the diagnosed breast cancer members of my family (and myself as a previvor), researchers do not have access to the collective pool of our samples, nor do they know they are all from one family with an unknown breast cancer gene.*	By enabling families to link their biospecimens and shared histories, a networked approach could uncover genetic patterns otherwise missed in isolated samples. This collective contribution has the potential to drive discoveries, especially in families with strong but unexplained hereditary risk.
Unity	*Rarely does science change with one patient. But when you have ten, and ten to the second power, ten to the third power… all coming together in cells that are united in a lab, that's when science changes, and that's when medicine changes, and that's when thriving happens.*	Bringing together biospecimens from many individuals creates a collective force for advancing science and medicine. This sense of unity highlights the power of aggregated contributions to drive meaningful breakthroughs that benefit entire communities, not just individuals.
Gratitude	*If I'm contributing to any kind of research, if it can help someone else in the future, I'm grateful for that.*	Participants expressed gratitude for the opportunity to contribute to research that could help others in the future. This outlook reflects a broader societal value placed on giving back and advancing knowledge, even without direct personal benefit.
Translation	*Everybody should be able to have this research done because my tumor is not the same as the person next to me or the person next to them, and to have a standard protocol of treatment doesn't fit in our society.*	Participants emphasized the need for research to translate into personalized care, recognizing that individual differences in disease require tailored treatments. Expanding research access was seen as essential to moving beyond one-size-fits-all approaches and improving outcomes for diverse patients.
Compensation	*If people are taking our information and using it for their profit, they should share it… [patients] could benefit significantly financially if there was more help and more information.*	Participants raised concerns about fairness and equity, suggesting that if their biospecimens and data contribute to profitable research, donors should share in the benefits. This reflects broader conversations about reciprocity and financial acknowledgment in the research process.
Reciprocity	*If the researcher asks me for more samples, I'll ask him or her where to go and I will be there.*	Participants expressed a willingness to continue contributing when they felt valued and informed, highlighting the importance of mutual respect and ongoing communication. This sense of reciprocity underscores the need for researchers to engage donors as active partners.