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ORIGINAL ARTICLE

Responsiveness and adaptability in community engaged biobanking research: experiences from a Hispanic community

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Abstract

The success of biobanking research relies on the willingness of the public to provide biological and sociological information, donate tissue samples, and complete psychosocial questionnaires. Medical advances made through biobanking research have limited reach if tissues are not obtained from a diverse sample of individuals. Within, we describe the process of transitioning a small group of Hispanic community members who met regularly into a more formal Hispanic Community Advisory Board (HCAB) for the Genotype-Tissue Expression (GTEx) project. The sole purpose of the HCAB was to provide input and feedback on GTEx and, specifically, how researchers can best address the concerns of the Hispanic community related to tissue donation. This initial purpose was adapted to be responsive to the HCAB's request to include educating others in the Hispanic community who were not a part of the advisory board about genomic biobanking. While HCAB members' knowledge of biobanking was limited, a strong need for culturally tailored information about the impact of biobanking medical discoveries and their potential benefit to the Hispanic community was expressed. The HCAB's feedback guided revisions to GTEx study documents to specifically address concerns about language use, clarity, and context including the need for consent forms to address cultural concerns and fears. HCAB members also collaborated on the development of a walk-through exhibition which provided a visual, narrative-based explanation of GTEx and the process of tissue donation for research and biobanking purposes. The HCAB demonstrated the value of including community participation in scientific research projects, for both scientists and lay communities, and underscored the importance of developing community engagement approaches that are adaptable and responsive to community needs. Our experience with the HCAB serves as exemplar for a unique paradigm of community inclusiveness and education in research.

Keywords Tissue banks · Genomics · Hispanic Americans · Community participation

Genomic biobanking research has become an integral part of the medical research portfolio in the USA and has already led to several groundbreaking medical advancements with far-reaching impact (National Institute of Health 2015). Yet, public knowledge of biobanking currently ranges from limited to non-existent. Views about biobanking are often informed by misperceptions and general distrust of the research process, researchers, and related institutions (Dang et al. 2014; Erwin et al. 2013; Luque et al. 2012; Rahm et al. 2013). The misuse of tissues, as highlighted by cases, such as the Havasupai Indian tribe, Henrietta Lacks, and others (Newkirk 2016; Smith 2013; Zimmer 2013), has heightened concerns about

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researchers' motives, increased doubts about the true beneficiaries of scientific advances, and reinforced mistrust within minority communities (Luque et al. 2012). Moreover, concerns about confidentiality, the misuse of genetic information, and a lack of familiarity with biobanking terminology are major barriers to biobank donations (Dang et al. 2014; Etchegary et al. 2013; Godard et al. 2004; Goldenberg et al. 2011; Lemke et al. 2010a; Luque et al. 2012; McCarty et al. 2008; Rahm et al. 2013). The need for adaptable and targeted community engagement efforts in biobanking research (Dang et al. 2014; Rodriguez et al. 2016; Streicher et al. 2011) is underscored by the aforementioned issues along with the imperative to include diverse populations in research to assure that everyone benefits from the genomics revolution (Horowitz et al. 2009). These issues are of even greater importance with the current federal government's major initiative, *All of Us*, to ensure diverse representation of different ethnic and racial groups (National Institutes of Health 2018). It is therefore critical to fully understand the nuances associated with engagement of diverse, ethnic populations to ensure that national efforts such as *All of Us* are representative of the US population.

This paper describes our experience engaging lay members of the Hispanic community to inform the implementation of a national biobanking project, the Genotype–Tissue Expression (GTEx) initiative (Carithers et al. 2015). The impetus for seeking feedback from Hispanics, in particular, arose through the systematic observation from GTEx data indicating noticeable lack of participation from Hispanics; Hispanics' refusal rate to GTEx participation was higher than that of African Americans (Genotype-Tissue Expression Project (GTEx) 2015). These concerns compelled the research team from the Ethical, Legal, and Social Issues sub-study to seek perspectives on GTEx from lay members of the Hispanic community. In particular, we sought to elicit concerns about donating posthumous tissues from a deceased family member to a genomic research project that could inform the GTEx study. Herein, we describe the process, form, and results of this engagement.

The GTEx project

Predating the *All of Us* initiative (National Institute of Health 2015), GTEx was funded by the National Institutes of Health's (NIH) Common Fund to examine the relationship between gene expression and common diseases by collecting biospecimens from healthy organ and/or tissue donors (Carithers et al. 2015; GTEx Consortium 2015). In partnership with six geographically dispersed Organ Procurement Organizations (OPOs), the NIH collected multiple reference tissues from over 900 donors (GTEx Consortium 2015). Five of the six partnering OPOs were managed by the National Disease Research Interchange (NDRI) in Philadelphia, PA. The collaborating OPOs approached family members of deceased organ and/or tissue donors (FDM) to request the donation of additional tissues specifically for GTEx biobanking and research purposes. Blanket authorization was obtained from all participating FDM which included the donation, preservation and biobanking of various tissues, the release of the deceased's medical and social history, and, when medically suitable, the donation of the whole brain to GTEx. The donated tissue was then released to the project biobank and an independent academic institute fully sequenced and analyzed the donor's genome for gene expression. Secondary researchers gain access to the genomic results through the NIH's online database of genotypes and phenotypes (dbGaP). The full dataset (including medical and social history, and genomic information) is restricted to qualified researchers who agree to follow NIH/NDRI ethical guidelines for use and promise to never attempt to identify the donors (Keen and Moore 2015).

The GTEx project also included the Ethical, Legal, and Social Issues (ELSI) sub-study that was tasked with exploring the effectiveness of the GTEx donor consent process. The major goal of the ELSI sub-study was to better understand families' donation decision-making as well as knowledge and attitudes concerning key social and ethical issues, such as confidentiality and return of results (National Human Genome Research Institute 2016). The methods and results of the ELSI sub-study are reported in detail elsewhere (Siminoff et al. 2016; Siminoff et al. 2017, 2018).

Community engagement in biobanking research

The success of genomic biobanking research relies on the willingness of the public to provide intimate biological and sociological information, donate tissue samples, allow access to medical records, and complete psychosocial questionnaires. The samples and corresponding data enable researchers to link specific genes to diseases and make significant scientific discoveries regarding disease initiation, progression, and treatment (Burchard et al. 2003). However, the medical advances made through biobanking research have limited reach or impact if tissues are not obtained from a diverse sample of individuals (Rodriguez et al. 2013). It is critical that tissue samples are reflective of the racial/ethnic and sociocultural diversity in the population so that comprehensive and nuanced explanations for disease prevalence and management may be achieved. For example, Hispanics are the fastest growing ethnic group in the USA (Colby and Ortman 2015) and are 1.7 times more likely to have been diagnosed with diabetes and twice as likely to have and die from liver cancer than non-Hispanic whites (United States Department of Health and Human Services Office of Minority Health 2016), but

Hispanic women are 30% less likely to have breast cancer than white women (United States Department of Health and Human Service Office of Minority Health 2016). The underlying social and biological causes of these associations may be more fully understood when the sample of donors accurately reflects the demography of the population, and between- and within-group differences may be more closely examined. Yet, Hispanics and other ethnic minority groups have donated tissues for research purposes at much lower rates than Whites (Shaibi et al. 2016). Increasing ethnic minorities' participation in biobanking efforts is now recognized as essential to ensuring a diverse donor pool and medical discoveries that will benefit all groups (Christensen et al. 2010; Lemke et al. 2010a; Streicher et al. 2011). Thus, realizing the full population impact of biobanking is highly dependent on public trust and participation (Etchegary et al. 2013; Lemke et al. 2010b). Ensuring participation from the entirety of the US population so that all benefit from new genomic technologies will require engaging communities in ways that create awareness, garner trust, and inform the science of the needs and preferences of individuals from culturally diverse populations (Shaibi et al. 2016).

The scientific biobanking community has typically sought public participation through methods such as focus groups and surveys, the results of which have been used to tailor materials and procedures for relevance to and comprehension by the target community and as means of adequately addressing concerns (e.g., ensuring terminology is culturally appropriate, changing wording of consent form for comprehension, or providing hotlines to answer questions) (Allyse et al. 2015; Kimball et al. 2014; Lemke et al. 2010b; Meade et al. 2015; Shaibi et al. 2016). In contrast, strategies to effectively engage diverse communities are grounded in models highlighting the broader context, including a community's history and existing relationships with the research enterprise (Den Broeder et al. 2016). Principles of participatory engagement such as fostering mutual benefit, providing opportunities for co-learning, and meaningful impact of participation serve as guide posts for biobanking engagement efforts (Minkler and Wallerstein 2003). There is a great need to increase public knowledge about biobank participation especially among underserved minority populations (Bonham et al. 2009; Rodriguez et al. 2016). While minorities are interested in learning more about biobanking donation, and altruism and collective benefit appear to be important motivators (Streicher et al. 2011), educational activities must be inclusive as well as comprehensible (Dang et al. 2014; Rodriguez et al. 2016).

CABs

Community Advisory Boards (CABs) are an important cornerstone of participatory research and an effective mechanism through which to seek input, foster trust, and help shape practice and policies. An important participatory principle that undergirds the work with CABs is co-learning and the idea that both researchers and community members have expertise and knowledge to share (Lemke et al. 2010b; Yarborough et al. 2013).

Working collaboratively with a CAB as a participatory strategy to provide overall guidance, direct participation, and more proximate feedback has proven useful in several biobanking studies (Strauss et al. 2001). CABs have been utilized specifically to provide input on biobanking efforts to ensure they are culturally responsive, consider various ethical concerns, promote transparency, and increase public trust (McCarty et al. 2011). CABs often focus on ethical concerns and serve a checks and balances function in the biobank's governance (Haldeman et al. 2014; Mongoven and Solomon 2012; Strauss et al. 2001). In particular, CABs have been used to improve the biobanking consent process by identifying ambiguities and areas of potential misunderstanding and providing community perspective on the process (Allyse et al. 2015; Strauss et al. 2001). Within the Hispanic community, CABs have been especially important in facilitating trust between the lay and scientific communities, identifying and removing barriers to participation, and establishing buy-in for research projects (Vincent et al. 2013). In one study, for example, the CAB mediated fears stemming from the passage of anti-immigration legislation (Gordon et al. 2015; Vincent et al. 2013). Hispanic CABs have also guided and informed the development of culturally appropriate recruitment and educational materials by providing feedback on language, terminology, images, and even the format of materials (e.g., using a "telenovela" format for educational videos) (Gordon et al. 2015; Kim et al. 2005; Vincent et al. 2013).

The use of CABs has not been without challenges (Simon et al. 2011). There are concerns that engaging with CABs may be unidirectional and solely benefit researchers' needs. A potential challenge of engaging CABs in biobanking discourse is that individual members may hold little to no knowledge of biobanking, which can affect both the extent and quality of input. CABs generally focus on engaging stakeholders who have some preexisting experience and/or knowledge about the issue for which their participation is sought (Rodriguez et al. 2013). Indeed, effective participation in CABs presupposes certain knowledge, familiarity, or interest with the issue. Biobanking-focused CABs will necessarily discuss a multitude of topics including tissue donation, research, risks and benefits of participation, and future uses of tissue (Lemke et al. 2010b). Therefore, CABs comprised of lay community members will need to ensure a baseline level of knowledge about biobanking and genomics among CAB members to be effective. Furthermore, it is important that the purpose for CAB member participation is clearly communicated to minimize the potential for further mistrust, particularly, in cases where researchers may be interested in utilizing the CAB for future recruitment purposes (Newman et al. 2011).

One of the critical questions for the twenty-first century and for national projects such as *All of Us* (National Institutes of Health 2018) is how to effectively engage diverse stakeholders in an informed discourse about genomic biobanking, a highly technical and medically complex subject. This paper will explore our approach to addressing this knowledge gap and describe our process of regularly meeting with a small core group of lay members of the surrounding Hispanic community who transitioned into a more formal Hispanic Community Advisory Board (HCAB) and identified their own informational needs about donation and biobanking. We also discuss how the research team responded to the needs and preferences of the local Hispanic community. The ELSI sub-study protocol, including engagement of the CABs, was approved by the Institutional Review Boards at Virginia Commonwealth University and Temple University.

Methods

From November 2013 to September 2015, the GTEx/ELSI team engaged members of the Hispanic community who had no prior experience with biobanking to seek their perspectives on the consent/authorization process, consent language, and general concerns with the GTEx biobanking project. After each HCAB meeting, the research team developed a memo debriefing NIH/NDRI on the HCAB's work. This paper draws extensively from these memos, observational data, and field notes documenting the process of convening the HCAB as well as the planning and implementation of two major educational initiatives.

HCAB recruitment

To inform our approach to recruiting board members, we consulted with respected leaders of the local Hispanic community. In particular, we communicated the purpose of HCAB participation which primarily focused on seeking input to inform GTEx processes and highlighting concerns of the Hispanic community related to GTEx. Across multiple individual and group meetings, we shared information about GTEx, tissue donation for biobanking and research purposes, the relevance of genomic research to Hispanics and other underrepresented ethnic communities, and the need to incorporate perspectives from the Hispanic community. We also discussed CABs as a mechanism for seeking regular input on issues related to genomic biobanking.

Based on the feedback obtained from community leadership, we held at least three informational presentations at a local community center during church services, ESL classes, and community health worker programs to recruit HCAB members. Each presentation included information on genomic biobanking and the importance of incorporating perspectives from underrepresented minorities to ensure equitable benefits to all groups. Individuals interested in learning more about the HCAB and its charge were asked to provide their name and contact information. To demonstrate their support, Hispanic leaders attended the presentations and were available to answer any questions. Twenty-four individuals provided contact information. To be eligible to participate, interested individuals must have identified as Hispanic/Latino, been 18 years of age or older at the time of recruitment, and possessed a strong interest in research and its relevance to the Hispanic community.

Setting and format

Meetings were held bimonthly from November 2013 to September 2015. All HCAB meetings were held at the Sacred Heart Community Center (SHCC) in Richmond, VA. SHCC is well-respected and trusted within the local Hispanic community and serves as a central educational and spiritual hub. Each meeting began with a social period, during which food was served and the members were afforded the opportunity to get to know one another and the research team. Additionally, undergraduate research staff was on site to provide childcare. HCAB members received a $25 stipend to cover the cost of travel and parking.

Meetings were initially conducted in both Spanish and English; however, since all members were fluent Spanish speakers, subsequent meetings were held exclusively in Spanish. On average, 10 to 15 individuals attended each meeting, of which there were a core group of five to seven regular attendees. Typically, several HCAB members brought children, spouses, or/and friends, which resulted in an open-door, revolving HCAB. The open group increased the HCAB's diversity in terms of age, education, and sex; it also allowed more community members to learn about GTEx and provide input on biobanking. However, this open format posed a challenge since each meeting began with a repetition of previously discussed key concepts. It quickly became clear that an understanding of organ donation and transplantation concepts were prerequisites for understanding biobanking. Reviewing the basic concepts at each meeting to bring new members up-to-speed delayed the research team's ability to move the discussion into biobanking topics. We subsequently re-evaluated the group and determined that a core group of seven regularly attending members would be approached to be part of a more formal HCAB (see Table 1 for a timeline of the meetings).

Laying the groundwork

Despite self-reported variation in socioeconomic status, education level, country of origin (Mexican, Colombian, and

Table 1 Hispanic Community Advisory Board timeline

November 2013	Meeting with community stakeholders; introduced the ELSI study, discussed objectives of the GTEx project, stakeholder input
February 5, 2014	1st meeting: introduced GTEx and how joining the board could help share the Hispanic perspective on GTEx
April 2, 2014	2nd meeting: ice breaker activities, discussed research, went over social network questions and assignment
June 25, 2014	3rd meeting: social network questions exercise follow-up, discussed organ and tissue donations
July 15, 2014	Weekly research team meetings with Hispanic leaders about the progress of the ELSI project
August 27, 2014	4th meeting: discussed organ/tissue donation; guest speakers from donate VIDA and WRTC. Reviewed the Spanish version of the consent form and suggestions sent to NDRI
October 22, 2014	5th meeting: WRTC speaker gave a presentation on the donation request process; reviewed steps of the GTEx consent process with visual aids
January 21, 2015	6th meeting: smaller core meeting. Discussed NDRI's memo on addressing the 's concerns with the consent form; discussed the walk-through GTEx exhibition
February–March 2015	Research team met one-on-one with each member to collaborate on the walk through biobank
March 18, 2015	7th meeting: presented a PowerPoint of the rough draft educational posters for the walk-through GTEx exhibition and solicited feedback; suggestions lead to a more info-graphic presentation of the material so it was easier to digest; team hired a graphic designer.
May 27, 2015	8th meeting: planned the details of the walk-through GTEx exhibition
July 29, 2015	9th meeting: finalized the logistics and content of walk through biobank
August–September 2015	Worked with members and others to invite Hispanic Community members to the exhibition; team finalized presentation with input
September 30, 2015	Walk through biobank exhibition

Peruvian), and US residency status, most HCAB members lacked basic information about tissue donation in general and held only a limited understanding of transplantation. Most members had heard of organ donation, but commonly conflated organ and tissue donation. This knowledge gap proved problematic because GTEx tissue samples were inextricably linked to biobanking, genomic research, and the source of the tissue—deceased organ and tissue donors. Subsequently, we used HCAB members' existing framework of organ donation as a point of reference for establishing an understanding of tissue donation. HCAB members unanimously agreed that there was a significant lack of education surrounding organ and tissue donation in their communities. Guest speakers from various organ donation organizations, including Dona Vida (Donate Life) and the Washington Regional Transplant Community, were invited to share information about organ donation and to address misperceptions about donation; the parish priest also attended a meeting to address religious concerns about donation. One concern was equity: HCAB members stated it was unfair that undocumented immigrants are considered eligible to donate organs but prohibited from receiving an organ transplant, if needed.

To aid the HCAB's understanding of research, we designed a graphic handout depicting the scientific method using the GTEx project as the example (see Fig. 1). Core elements of basic medical and social behavioral research were explored through the use of the graphic.

Once a shared foundational knowledge about and comfort with organ donation was established, we provided more details about GTEx and tissue donation. Specifically, we developed an interactive training module, which included information about tissue donation and the mechanics of basic and social behavioral research. Each 90-min meeting began with a module, and transitioned into discussions about specific GTEx issues, such as the consent procedure, the role of the extended family in donation decisions, and the appropriateness of the authorization forms. We created a life-size drawing of the body and used stickers to identify organs and tissues that are part of the GTEx request and outlined the steps to GTEx authorization (see Table 2). Other visuals developed to facilitate the HCAB's understanding of GTEx were the image of six stacked dimes as reference for the size of the tissue aliquots.

Input on informed consent forms HCAB feedback was sought from NIH/NDRI about the GTEx website and the informed consent document. Upon request, HCAB members individually reviewed the publicly accessible GTEx website for visual appeal, readability, and content appropriateness. HCAB members also provided critical feedback on the Spanish version of the GTEx authorization/consent form, from the size of the font to significant concerns about missing and ambiguous information. The GTEx authorization/consent document was translated into Spanish by a professional translation company. Unpublished internal GTEx records show that fewer than 40 potential GTEx donors were Hispanic of which only 21 (52%) became donors; the ethnicity of potential donors was missing in 30% of cases. HCAB reactions to the GTEx consent first focused on language and translation issues. HCAB members felt that the consent form was densely worded; however, they

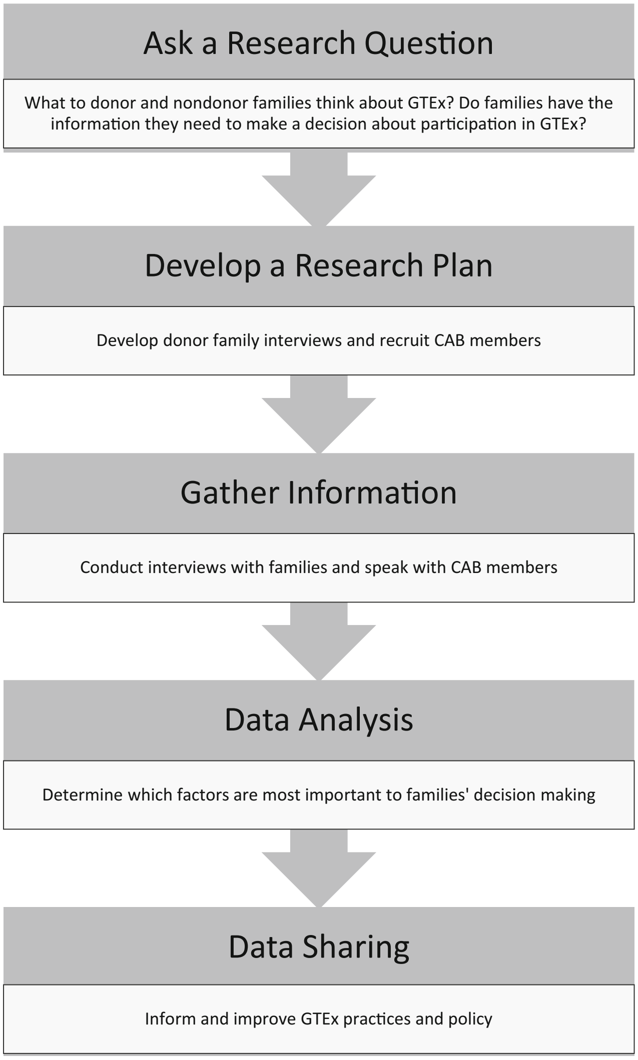

Fig. 1 Scientific method handout

Table 2 The steps to GTEx authorization

Authorization process: donor
1. Patient signs up for donor registry or designates donor status on driver's license
2. Patient falls ill/has accident where recovery is extremely unlikely

Authorization process: donor's family
3. Patient's family is approached by tissue requestor to discuss donor status and possible donation
4. Patient is pronounced brain dead
5. Patient's family immediately meets with tissue requestor to discuss specifics of donation
6. Family consents to organ and/or tissue donation
7. Tissue Requester discusses possibility of donation to GTEx biobank
8. Family is read GTEx authorization form and consents to donating tissue to the biobank
9. Family is provided time to say goodbye to loved one

Surgical process
10. Patient undergoes surgical procedure to obtain GTEx tissues (In the case of tissue-only donors, whole brain donation is required in addition to tissue samples)
11. Patient is made to look presentable for open casket funeral/viewing through reconstructive process

were unequivocal in their preference for a detailed consent form with unambiguous language. Additionally, the HCAB indicated that the English translation was too literal and identified several instances of awkward and erroneous phrasing and vocabulary usage. Of note, they found information in the English consent form that was not well translated into Spanish. For example, one participant said: "in English we read prostate, testes, ovary, vaginal tissue and uterus as well as definitive muscle tissue, while in Spanish these terms are lumped under the vague 'tejido reproductivo' (reproductive tissue)." They indicated that if tissues are specifically referenced in the English consent, they need to be included in the Spanish version, as well. This sentiment conflicted with statements from members suggesting that not everything in the English consent form can or should be translated verbatim into Spanish. For example, the English consent form contains reference to removing tissue samples the size of six stacked dimes. Members had questions about the types of coins and highlighted that coins vary in size and suggested that it could be confusing particularly for Hispanics who frequently originate from different countries and, therefore, may misunderstand the size of the coins. Furthermore, members indicated that the term used for research in the consent form could imply a "legal investigation" especially to those who are unfamiliar with biomedical research. Concerns about funeral logistics emerged as a critical issue and members suggested that the consent form should openly address these concerns. These observations and recommendations were delivered via written memo to the NIH/NDRI.

Educational initiative 1: SNAP

While CABs are an important strategy for promoting public participation and eliciting local perspectives, most are comprised of only 5–10 members limiting representativeness and breadth of responses (Safo et al. 2016). To obtain perspectives beyond that of the HCAB, we designed and implemented an innovative social networking exercise with the Hispanic community members ($n = 10$). The goal was for members to convene small groups of friends and family for informal conversations about research and biobanking. Members were provided $50 to fund refreshments for home-based, small group discussions. Questions and prompts developed by the research team were also provided for use during the discussion. These included the following: What comes to mind when you hear the word research? What about medical research? Have you ever participated in medical research? In general, how do you think medical research impacts your community? What types of information would you like to receive regarding tissue/

organ or GTEx donation? How would you like to receive this information? Who should deliver such information?

HCAB members were successful in recruiting family members and/or friends to participate in group discussions; all members reported that they had interactions with at least two friends or family members. After each discussion, members were debriefed on the content of their discussions. HCAB members digitally audio-recorded the discussions and submitted the recordings to the research team for transcription and analysis. Results revealed that participants in the group discussions had only a vague understanding of research and biobanking. Individuals in members' networks had a greater understanding of "medical research" than "research" generally, although the term was associated solely with clinical research and not the wider spectrum of basic or other types of research. This was not surprising given that neither of the members nor anyone in their respective social networks had ever participated in a research project. Both members and their networks reported the need for more details about organ donation, more transparency about the reason tissues are used and why, and greater explication on the association between tissue donation and abortion. Both groups requested the delivery of information about tissue donation information come from a credible source—someone affiliated with a university, hospital, or research institute.

The social networking activity not only provided the HCAB with an opportunity to engage friends and family in conversations about research and tissue donation, but it also offered the research team a unique glimpse of the lay Hispanic community's understanding and perceptions of biobanking and the donation of human tissue for research. This information informed the content of the CABs' second project—the walk-through GTEx exhibition.

Educational initiative 2: walkthrough biobank

Recognizing the considerable gains in knowledge and insights about organ donation, biobanking, and research acquired through their service on the board, the HCAB expressed a desire to inform the surrounding Hispanic community of the benefits and need for biobanks and medical research. Specifically, they suggested a community event to introduce lay members of the local Hispanic community to GTEx and provide information about the process and outcomes of tissue donation for research purposes. The goal of the walk-through biobank exhibit was to provide an interactive, visual narrative tracing a hypothetical GTEx donor's tissues and medical information from the authorization process to therapies potentially made possible from data derived from the donor's tissue.

As part of designing the exhibit, the research team met individually with each of the seven members to elicit perspectives on what a walk-through GTEx exhibition would look like and need to address. The information gleaned from these meetings, in addition to the steps to GTEX authorization that was previously identified (see Table 2), was incorporated in mock-ups of content for each "station." Across several meetings, HCAB members critiqued and provided feedback on the mock-ups. Key feedback points included the need for materials to be primarily visual and concisely explained without oversimplifying as well as avoiding long passages of text or use of jargon. Ultimately, four posters were designed and developed to provide an overview of the GTEx process: (1) tissue collection, biobanking, and consent processes, (2) storage of GTEx tissues and data, (3) the process of turning the tissue into "data" and for researchers to access GTEx data and tissues, and (4) how GTEx might advance science and medicine and the potential impact on donor families and the public. The HCAB was also instrumental in the inclusion of a fictitious deceased Hispanic donor, Miguel, as a relatable focal point linking all concepts discussed at the four stations. A graphic designer was hired to create Spanish and English versions of the posters. Both HCAB members and members of the research team provided feedback on all drafts. The posters (see Fig. 2) were printed and loaded into floor-standing, retractable banners, which aid in ease of display, storage, and portability.

The culminating exhibition and walk-through biobank was held at the SHCC. At the opening of the exhibition, attendees viewed a video (https://vimeo.com/user31429536) that provided important contextual information about how GTEx approaches are made to families of posthumous organ donors. The video was part of a GTEx tissue requester training intervention in the larger ELSI sub-study. The video was in English with Spanish subtitles. The video further illuminated the concepts explored in the posters. After viewing the video, attendees were invited to visit the posters, which were displayed around the event hall. Refreshments were catered by a local Hispanic businesswoman recommended by the HCAB. HCAB members held key roles at this event, including welcoming and hosting guests for the evening and fielding questions at each poster station. Donate Life and LifeNet Health Tissue Services were on site to provide attendees with information in Spanish. A nine-item pre- and post-survey was administered before and after experiencing the walk-through exhibition.

Forty participants attended the exhibition and completed the surveys. Attendees included family and friends of the HCAB members as well as members of the broader community. Overall, less than one third of the attendees completing the survey had ever heard the word "biobank" and only slightly more (37.5%) had heard about tissue donation for research. The majority of attendees reported the posters to be very informative and the presentation about GTEx "very interesting." When asked if they learned something that they did not know before attending the exhibition, one respondent noted, "…a very small donation makes a big difference. I didn't know anything about tissue donation for research and I think it's very important to know." When asked if there was anything else they'd like to know about

Fig. 2 Four posters created with the Hispanic CAB to explain the GTEx project to community members. The posters cover both graphically and with text: tissue collection, biobanking, and consent processes; storage of GTEx tissues and data; the process of turning the tissue into "data" and for researchers to access GTEx data and tissues; and how GTEx might advance science and medicine and the potential impact on donor families and the public

GTEx or biobanking, attendees answered: "I'd like to know about the legal regulations and the benefits for future generations" and "how to become a donor."

Discussion

Engaging individuals with no previous experience or knowledge of biobanking in a genomic advisory board is a challenge that must be addressed by various stakeholders, including public health researchers and scientists, as part of the critical task to increase the diversity of public participation in genomic biobanking and research (Etchegary et al. 2013; Godard et al. 2004; Lemke et al. 2010b). Furthermore, the ethical, social, and legal issues associated with tissue collection from return of results, ownership, and use of tissues to the various ethical violations (Nisbet and Fahy 2013; Smith 2013) associated with the use of tissues necessitate the need for best practices regarding public engagement (Bledsoe 2017). Driving the need to develop and implement strategies that maximize public participation in genomic biobanking, as well as inform public education efforts prior to experiencing a request for tissue donation, is the high refusal rate for tissue donation among underrepresented ethnic minorities (Dang et al. 2014; Oh et al. 2015). As noted above, GTEx had the highest refusal rates from Hispanics (48%) even when compared to African Americans (40%). Therefore, a CAB can provide insightful information that can serve as guidance to researchers and others about potential barriers to tissue donation.

The question of how to meaningfully engage the general public in discussions about biobanking is critical. In this study, the use of a multilayered engagement approach was important to our success. First, we approached credible leaders in the target community explaining the purpose of a CAB. This first stage was necessary to establish trust, answer questions, and develop a basic understanding of concepts associated with tissue donation for research. This was followed by outreach to smaller community groups and hosting several "open forums" before we were able to establish the HCAB. Our outreach efforts were further expanded to include engagement and input from the social networks of the HCAB members. Importantly, HCAB members emphasized that friends, family, and others in the Hispanic community also be informed about biobanking and GTEx. Finally, we incorporated use of town hall style meetings as means of educating the larger lay community about GTEx and biobanking. Furthermore, our work highlights the importance of being adaptive to the needs of the advisory board members beyond the stated goal of the researchers. Although not an original goal of the ELSI sub-study, we developed the walk-through GTEx exhibition as a response to the need to provide biobanking information to others beyond the HCAB members. Social network outreach such as the Social Networking Project (SNAP) and townhalls may be easily replicated to extend the reach of engagement efforts beyond that of the CAB.

Understanding and acknowledging resource limitations are also essential for successful community engagement, particularly when asking community members to engage in public health issues that may not be salient to them. For instance, through the provision of stipends and child care during HCAB meetings, we were able to address economic and logistic barriers which facilitated greater participation in the meetings. In this study, we were also able to provide resources to address the HCAB's identified need for a community townhall meeting with visual educational displays. It will always be a challenge for researchers and program staff to balance available resources and adequate community appreciation and responsiveness. However, if researchers are transparent about their goals and resources (or lack thereof) and CAB members are approached as partners in the process, agreeable solution is more likely to be reached.

The general public has little awareness of the benefits and risks associated with tissue donation for research purposes, and therefore, the question of how to engage them in this discourse is of paramount importance to ensure a diverse pool of tissue donors (Rahm et al. 2013). The question as to how researchers and practitioners might discuss this complex topic with underrepresented ethnic minority communities in a manner that recognizes historical and contemporary inequities, previous ethical violations, and scientific misconduct was at least partly answered through this work. The HCAB suggested that recruitment information should identify and highlight benefits to the Hispanic community accrued through the donation of tissues for biobanking and genomic research as well as share unintended societal consequences of non-participation. Through an ongoing dialog with the research team, HCAB members increased their understanding of organ and tissue donation and developed an appreciation for the scientific breakthroughs made possible by medical research. These attributes became anchors for subsequent discussions about biobanking.

A valid concern with CAB participation is the extent to which members may be co-opted by the researcher's agenda (Cornwall and Jewkes 1995). There is expectation that some member's views may become more favorable as concerns are addressed and clarification is provided about the genomic biobanking process. However, even as the HCAB members came to recognize the scientific safeguards in the GTEx process, they continued to express concerns related to equity and, in particular, that undocumented immigrants were prohibited from receiving an organ transplant even though organs from such immigrants are accepted. It is important to note that this HCAB concern never wavered suggesting that "genetic literacy" still has to be aligned with the participant's values and beliefs for it to be perceived as credible. Therefore, targeted recruitment, clear expectations of CAB member purpose, and researcher transparency can reduce CAB member potential co-option.

What started as an unknown, potentially intimidating subject became a topic about which members later considered themselves to be knowledgeable, as demonstrated by their facilitation of the SNAP discussions and role in answering questions from community members at the exhibition. This study demonstrates the feasibility of engaging the public on complex topics such as genomic biobanking. However, effective, meaningful community engagement requires equitable collaboration wherein researchers work with members of targeted communities to construct a shared meaning of the topic and related issues and co-design educational materials that honor cultural traditions and values, and are sensitive to existing knowledge levels and responsive to community concerns.

Another important consideration when establishing a CAB is the issue of sustainability through building capacity at the individual and community level. We acknowledge that most education programs, including the one in our study, are time limited. Thus, sustainability is seen as a function of community members continuing to share their knowledge and demystify concepts procedures and outcome associated with genomic biobanking with others in the community. We can learn from cancer survivor models of engaging the survivor as educator (Saad-Harfouche et al. 2011) and train those with experience in tissue donation: family members who have lost a loved one and donated to a biobank are often highly motivated to share their experiences and to provide personal testimonies. Creative and personalized methods such as house chats (members of social circle disseminating information) (Mosavel et al. 2016) and reaching-in to community at places where they typically gather (churches, etc.) (Campbell et al. 2007; Linnan et al. 2014) and directly inviting community members to share their concerns can maintain the momentum of the initial education program.

A limitation of many CABs is that input is restricted to the members in attendance at any given meeting. While we maintained a core group of committed HCAB members, attendance at meetings ranged from 5 to 20. The social networking task facilitated broader assessment of the community's understanding of tissue donation and biobanking. This strategy can be useful for others interested in incorporating the views of a larger group. It is important, however, to establish a core group that is diverse in age, gender, or any other criteria deemed important. Members are likely to reach out to others similar to them. Additionally, the generalizability of our approach is limited to our experience with one Hispanic community in the mid-Atlantic region of the USA.

There were other lessons learned from engaging with the Hispanic community. Foremost is the importance of integrating input from the general public, as well as more targeted feedback from ethnic and economically diverse communities into practice. The success of obtaining diverse tissue samples is highly limited if scientific communities do not make this a priority. Key stakeholders central to genomic biobanking efforts include academic researchers, basic scientists, institutional review boards, and OPOs. Seeking feedback must necessarily be accompanied with a realistic plan for implementing the requested perspectives or recommendations and must go beyond a checklist approach where seeking input itself is the outcome. Second, the timing of engaging communities is crucial in determining whether the requested input can be incorporated into practice. While it is unrealistic to expect that all recommendations will result in protocol changes, there must be an increased openness and commitment from researchers and others to meaningfully incorporate community input into study designs. At minimum, we recommend seeking feedback during the planning stages; however, engagement can and should occur on an ongoing basis. Genomic biobanking efforts must adopt a model of community engagement that regards community members as an essential stakeholder group whose input is sought with the intention of informing biobanking processes. If the goal is to include all segments of the population in initiatives such as precision medicine, it is imperative that researchers and practitioners also create systems and practices that are adaptable to incorporate community feedback. Finally, to be effective, engagement efforts must be equitable, bi-directional, and varied; such efforts must also be culturally tailored to address the information needs and honor the concerns and values of targeted communities. Systemic changes are needed to biobanking research processes to expand the diversity of biobanking samples. Developing best practices for engagement in biobanking will ensure the resulting therapies benefit all segments of the population.

In conclusion, the process and products of the GTEx ELSI HCAB can inform minority participation in future biobanking projects. Our approach to engaging the HCAB offers a roadmap for other research teams on how to reach, communicate with, and meet the needs of a population who have had little to no contact with biomedical research. The HCAB's impact on GTEx (i.e., website, consent forms, public education) demonstrates the value of including community participation for the project, scientists, and the larger community and provides a unique paradigm of community inclusiveness and education in biobanking and genomic research.

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Compliance with ethical standards

The ELSI sub-study protocol, including engagement of the CABs, was approved by the Institutional Review Boards at Virginia Commonwealth University and Temple University.

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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