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Translating Biobank Science into Patient-Centered Language

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Introduction: This project used Boot Camp Translation (BCT) to translate the complex medical jargon of biobanking into locally relevant evidence-based messages and materials to support increased knowledge and understanding in the local community.
Methods: Biobank BCT was a partnership of 16 community members and 5 academic researchers. The partnership met for 8 months.
Results: The partnership developed five main and seven submessages to assist patients and community members in making an informed decision about enrollment in a biobank.
Discussion: The resulting messages balance an individual's right to privacy and choice, while encouraging participation for the greater good.

Keywords: biobank, biomedical ethics, community engagement

Introduction

The development of opt-in, population scale biobanks may be a remarkable resource to facilitate genomics research and potentially discover new treatments and cures for devastating diseases.[1–3] If biobanks are to become a valuable resource for research, a large and diverse number of individuals must agree to donate personal information that includes some combination of blood, saliva, electronic medical records, and/or behavioral information depending on the biobank.[4] Unlike many research endeavors, biobank participants are not asked for consent to use their information for specific, narrowly defined research projects. Rather, participants must generally consent for their blood, tissue, and linked clinical and sociodemographic data to be used broadly for IRB-approved research that qualified scientists may seek to undertake.[5] Privacy, confidentiality, insurance, commercialization, and broad consent are just a few considerations that raise ethical concerns around biobanking, which ultimately could preclude individuals from participation.[6–9] Even the name biobanking can be intimidating and confusing to people, since biobanking is associated with complicated procedures and intricate language.[10] However, without broad community support for biobanks including racial and ethnic diversity in biobanked materials, potential scientific advances and the utility of biobanks in the fight against disease and health disparities are thwarted.[11,12]

The purpose of this project was to identify the essential information about biobanking that may assist patients and community members in making a knowledgeable and informed decision about whether to participate and enroll in a biobank. The project used the Boot Camp Translation (BCT) process to bridge the gap between complicated medical language and information necessary to make informed medical decisions.[13] BCT engages community members and academic researchers in the translation of complex medical information around a selected topic into locally relevant language and materials. For this project, the goal was to create messages and materials to generate opportunities for meaningful conversations between community members, patients, providers, and researchers about the complex scientific and ethical information about biobanking, leading to improved understanding of and possible enrollment in biobanks.

Methods

BCT is a robust 8-month participatory process that was developed by The High Plains Research Network Community Advisory Council and has been used in multiple diverse populations all over Colorado and the United States. BCT begins with a full-day kickoff meeting wherein patients and community members become relative experts in the clinical topic identified as a priority by the community. This is followed by a series of four to six short single-task phone

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calls and two to three additional in-person sessions wherein the local community identifies what they want to say and how to disseminate that message. Conversations in these calls and meetings are interactive and iterative. For 8 months, the community and research group learn together about the medical topic, craft messages they want their family and neighbors to know, and design dissemination methods to get the messages and materials into their community. Final messages are evidence based and locally relevant. BCT is able to provide a high level of scientific knowledge and understanding to community members with a variety of educational backgrounds and has been used successfully in numerous settings and populations.[14] A full description of the BCT process is provided elsewhere in the literature.[15]

The BCT reported here included a partnership of 21 persons from the Rocky Mountain region that included 16 community members (including 2 marketing professionals) and 5 academic researchers and clinicians. The partners provided a range of expertise as members of a variety of racial and ethnic communities, patients/parents of persons with genetic disease, community members with public health interest and experience, and academic researchers in primary care, genetics, bioethics, and health services researchers. Built on the principles of community-based participatory research, BCT recognizes partners' individual types and levels of expertise, as members create innovative materials and messages together.[16] Table 1 provides detailed information about the participants.

The key component of the first BCT meeting was a detailed scientific presentation. We used local and state medical experts to provide a 3-hour evidence-based presentation on biobanking and genetic research. The presentation was not geared to a ''lay'' audience, rather, it included the same information given to healthcare professionals. This presentation ensured all members had the same information. After the educational presentation, the BCT participants brainstormed and developed messages that would make the traditional complicated language associated with biobanking more accessible and meaningful for them and their neighbors. The group also began to consider methods for disseminating the new biobanking message to communities around Colorado, such as through local media or other materials. The group continued to meet by phone and in-person for 8 months until final messages were completed.

Results

During the first all-day session of BCT, the partnership provided initial reactions to the educational information. Overarching questions and concerns that were raised included what is a biobank, how can a biobank benefit the people in my community, what are the risks of biobanks, and how can people make informed decisions about their participation in biobanks? Table 2 lists initial topics and ideas, presented in the form of questions and messages to pursue.

One of the greatest concerns raised by community members was the value of privacy, including concern that biobank research and associated information might be shared with insurance companies. Another concern focused on the name ''biobank.'' Some members felt that the word ''bank'' sounded misleading, as it implies that a participant is able to make ''withdrawals'' of their sample from the bank. Several participants drew a connection between the word ''bio'' to words like ''bioterrorism'' and ''biohazard.''

The group also discussed the use of blood and tissue samples. With the knowledge that biobanks conduct large-scale genomic research with no guarantees that donating a sample will yield personal benefit, the group came up with a message that biobanks facilitate ''discovery'' research with

Table 1. Biobank Boot Camp Translation Participants

Participant No.	*Age group*	*Gender*	*Race/ethnicity*	*Career/job/experience*
1	50s	F	White	Community member—child with genetic disease
2	50s	M	White	Community member—child with genetic disease
3	40s	F	White	Community member—child with congenital, nongenetic health condition
4	20s	F	White	Young professional public health
5	60s	M	African American	Well-respected urban leader of a nonprofit community organization
6	20s	M	Indian	College student studying biology
7	50s	F	Latina	Community member
8	50s	M	White	Community member with history of cancer
9	50s	F	White	Community member
10	50s	M	Latino	Community member
11	60s	F	White	Community member, retired nurse
12	40s	F	Asian	Community member, mother, statistician
13	20s	M	White	Young professional
14	30s	F	White	Marketing professional
15	30s	F	White	Marketing professional
16	Unknown	F	Unknown	Community member
17[a]	50s	M	White	Family physician researcher
18[a]	40s	F	White	Public health researcher
19[a]	40s	M	White	Physician genetic researcher
20[a]	50s	F	White	Bioethics researcher
21[a]	20s	M	Asian	College student studying philosophy

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Table 2. Initial Brainstorm Topics and Ideas

What is biobank research?	*How might biobank research impact me?*	*Educational messages for me and my community*
What is a biobank?	What is the possible harm to me?	Your samples may be used for research that will not help you today, but it may help many people in the future.
How does DNA work?	How will my DNA help?	Biobanking is about research, not to create a treatment for you.
Who is doing the research?	Will the information be protected from the insurance company?	Biobanks store and use samples of blood, saliva, urine.
What does using the sample actually look like?	What does it cost?	DNA is needed from healthy people as well as people with health problems.
Is genomic data permanent and usable by others or do they need the actual sample?	What does my community need to know about biobanks?	Remove silos. Instead of individual researchers with single, topic-specific projects collecting samples, biobanks store samples for a larger community of researchers.
Biological samples are needed to access individual DNA and genetic information to do what?	How can a biobank benefit people in my community?	Samples are precious, limited in quantity, and the quality does not last forever. Do not let it go to waste.
What are the risks of biobanks?	Will I get paid if I participate?	You may be contacted if there is a new discovery about a genetic disease that you have.
How can people make informed decisions about biobanks?		If asked for a sample, you are not obligated to participate.
		Your samples may be used for research that will not help you today, but it may help many people in the future.
		Biobanking is about research, not to create a treatment for you.
		Biobanks store and use samples of blood, saliva, urine.

potential for positive impacts for the general population in the future.

An extensive discussion occurred around the tone of the messages. Based on the group's initial broad ideas, a tone continuum was created that ranged from ''neutral education'' to ''persuasive'' to ''civic duty.'' Participants viewed biobanking as an opportunity, not a civic duty, but they preferred a tone that was more than educational. The partnership concluded that although messages should include a mix of tones, most should have a persuasive tone and should invite people to action. They also recommended that the messages create a bridge between the science and relevance to the participants, specifically ''I need to see me here.''

The BCT partnership developed a set of five main messages to provide information and motivation, inviting participation, but clearly presenting participation as a choice, not a requirement. The group wanted messages to reach ''lots of folks'' but also some specific populations, including young adults, people with no known health condition, people from different racial and ethnic groups, and patients at the University of Colorado Health (UCH) system. Words and concepts considered particularly important to the community members are underlined.

- Biobanking stores your blood and tissue and its genetic data in a secure location for future research.
- Your participation in biobanks can lead to genetic breakthroughs.
- Your samples can facilitate discovery research.
- Participation is voluntary.
- You are invited to participate.

Seven submessages also emerged that the partnership wanted to include and expand upon in specific materials. These include:

- Biobanking is an opportunity to participate in discovery research.
- Genetic research can facilitate discovery of genetic markers that help determine best medication.
- Your sample is deidentified to help maintain your confidentiality and privacy.
- Only approved researchers have access to your genetic material and data.
- Genetic research needs participation from people with no known health issues and people with identified health issues.
- Participating in a biobank does not cost you anything.
- You will not be compensated for participating.

Community members also worked on a set of materials to disseminate the biobank messages to the UCH region. They recommended using multiple types of print educational materials to start the dialogue, with each including the main messages and then expanding upon selected submessages. A main dissemination strategy drafted and promoted by the group was a short video. The video balanced facts with humor and some playfulness, with the goal of broad reach but particular effectiveness with visual learners and younger

people. A video can address the voluntary nature of participation and ability to help others, and show clips of the laboratories and storage space to foster more trust between potential donors and the biobank. Both print and video materials should also include stories of impact describing the impact of biobanking. All materials should use real people from Colorado whenever possible.

The partnership specifically did not recommend certain materials, including a ''biobank card'' for participants as this held an unappealing sense of permanence and implied that the card holder needed to keep track of something. Finally, the group strongly recommended the development of a logo for all materials, such as a double helix blooming into something that represents health but not medications. Although not containing much specific information, a logo would relay the core values of the biobank.

Discussion

The BCT reported here was effective at identifying common themes and important language for messaging and tone. The BCT process intentionally presented information in the educational phase that contained an advanced level of information, since the purpose was for members to know more about the given topic than the community at large and to ensure all members started with the same basic understanding of the topic. Another aspect of BCT that this particular project highlighted was the need for strong facilitation skills. BCT was not like facilitating a focus group. It required unique skills that allow the person to serve as a participant-facilitator. Members' participation and responses in the biobank BCT may have been supported by strong facilitation, intent listening, and having their questions answered. However, we did not formally evaluate this component of the Biobank BCT.

Many of the messages identified in the BCT reported here are found in the published medical literature on biobanking and genetic research (privacy, confidentiality, discovery, ownership, return of results, etc.).[6–9] However, BCT participants were more balanced in the support and concern expressed by community members. Although some BCT participants felt like donating left-over blood samples to a biobank was a civic duty, similar to becoming an organ donor, there was enough concern about potential misuse of genetic data that the group as a whole backed off, endorsing this level of encouragement. Furthermore, the group felt that messages and materials should not scare patients away from participation and should be clear about the real potential for future health improvement. They wanted to initiate conversations about biobanking. They felt that an uninformed ''no'' was not better than an uninformed ''yes.'' Patients and community members should not simply dismiss participation without understanding the medical and social benefits, nor should they be automatically enrolled without their informed agreement.

There was consensus that strong governance and ethical oversight of biobank samples, operations, and research approval are required to limit the potential for misuse or financial abuse—and materials need to address this area. The group did not particularly like the term ''biobank.'' However, since the term ''biobank'' is used around the country, the group did not believe Colorado should use a different term and risk miscommunication and misalignment with national work and policies. BCT participants remained engaged throughout the process, actively working through difficult ethical issues already enumerated.[17–23]

Participants considered themselves patients and community members bringing their expertise, ideas, and opinions in both roles. Their community expertise provided a variety of cultural, gender, age, ethnic, and educational backgrounds and life experiences. Their role as patients provided a range of medical experience, including their own health and wellness, chronic medical conditions, genetic diseases, and experiences accessing healthcare. Because the group claimed the dual roles of patient and community members, the messages they created are more generally relevant to the community. Future BCTs might choose to include just patients and families with genetic conditions to more narrowly consider the risks and benefits of participation in a biobank.

Overall, the community members supported the benefits of biobanking, and this is reflected in the resulting main and submessages. Specific messages, particularly the action-oriented invitation message, can be more tailored to other local communities and groups that differ in race, gender, age, and socioeconomic status. This is important in two ways. First, representation in biobanks must include great diversity in order for the samples to be scientifically valuable. Second, without diverse participation, variants that cluster in different ethnicities will not be studied and, subsequently, those groups will not have access to potential advances in novel treatments and cures. Information and dissemination strategies developed in partnership with local community members and patients are necessary immediately and will become more important as precision medicine, which includes individual patient genetics, becomes routine clinical care. Our current dissemination efforts have focused on the UCH System patient population. Additional funding and support will expand the dissemination of our findings, including the locally relevant messages and materials, into the broader Colorado community. It was clear to our participants that although our messages about biobanking were more relevant and meaningful than before, the materials from our core Biobank BCT were not adequate to reach some ethnic and rural populations. Our participants have encouraged and supported our efforts to expand Biobank BCT to additional local communities, including rural and urban, specific ethnic groups, refugee communities, and patients with specific genetic conditions.

Conclusion

BCT successfully engaged a diverse group of community members to translate the evidence-based literature on biobanking into locally relevant, meaningful messages for Colorado. Although the primary and secondary messages may align with the published literature on biobanking, the nuanced language created by the community members sought to balance the tension between an individual's right to privacy and choice, while encouraging participation for the greater good of society.

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