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Introducing Biospecimen Science to Communities: Tools from Two Cities

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Abstract

Background—This article describes community-engaged processes employed by two Community Network Program Center (CNPC) sites located in Tampa, Florida, and Buffalo, New York, toward the development of Spanish/English educational products about biobanking and biospecimen research.

Methods—Each CNPC carried out a community-based participatory research (CBPR) approach that underscored six essential components that moved concepts to a final educational product in a highly participatory fashion. The similar CBPR processes at the two locations focused on the same topic, resulted in different engagement approaches and tools for their respective communities: 1) DVD and brochure toolkit and 2) PowerPoint, group program with audience response system (ARS).

Results—We detail a comparison of methods and applications for using these tools among diverse community groups to advance understandings about genetic and biomedical research technologies.

Conclusion—Ultimately, these tools and associated educational efforts emphasize the critical value of co-learning among academic and community members in biobanking and biospecimen research.

ACCESS TO TOOLS
Readers who wish to obtain a copy of the educational tools referenced in this manuscript are encouraged to contact the respective authors at their institutions. For the WNYC2 ARS presentation, please contact Dr. Elisa Rodriguez at Elisa.Rodriguez@RoswellPark.org. For the TBCCN tools, please contact Dr. Cathy Meade at Cathy.Meade@Moffitt.org.

Keywords

Community-based participatory research; community health partnerships; vulnerable populations; health promotion; health disparities

Participation of diverse individuals in biobanking initiatives is crucial to realize personalized medicine goals and address issues of limited generalizability present in current clinical and genomics research.[1–6] In light of the emergence of biospecimen science and the value of samples from diverse populations, two CNPCs—the Tampa Bay Community Cancer Network (TBCCN) and Western New York Cancer Coalition (WNYC2)—realized that educational tools could address an information gap for educating "healthy community members" about this topic. Creating greater understandings about biobanking—for example, What is it? Why is it important? And what does it mean to me and my family?—could support community members in making well-informed choices about whether or not to participate in biospecimen donation.

The timeliness of developing educational tools was particularly salient in 2008 through 2010 because of the expanding needs in our areas to involve the public in research processes. Existing educational tools at that time were mostly directed toward clinical biobanking considerations for the cancer patient (e.g., Dana-Farber Cancer Institute's *Advancing Cancer Care: Tissue Banking* [2007] or Moffitt Cancer Center's single leaflet about tissue donation for research, and the National Cancer Institute [NCI]'s brochure, How you can help medical research: Donating your blood, tissues and other samples [NIH publication no. 7933, August, 2012]). Further, these existing tools did not reflect local relevance and cultural–ethnic diversity for our communities. Therefore, consistent with the education and research goals of our two CNPCs, a number of plans for public engagement and transparency around this topic within our demographically diverse communities were put into place.[7–9]

A prerequisite to the conduct of biospecimen research is the need to invest time to develop community relationships, and to earn community trust through transparency, clear communication, and culturally and contextually appropriate education.[1,10] As such, our two CNPCs embarked on separate but unified journeys to improve understandings and cultural and literacy sensitivities about a new developing technology in oncology, namely, biobanking/biospecimen donation and research. Such communication priming tools could help community, academic, and clinical partners to engage their constituents when making a decision if or when approached to participate in biospecimen donation.

As background, TBCCN, formally established in 2005, serves the Tampa Bay, Florida region (Pasco, Hillsborough and Pinellas counties), and centers its efforts on medically underserved populations, which are ethnically and linguistically diverse (Hispanics, African Americans, Haitians and other Afro-Caribbeans, and Whites) and include a growing foreign-born population. Community outreach has been ongoing for more than a decade before the funding of the TBCCN. The WNYC2 established community partnerships in 2008, was funded as a CNPC in 2010, and serves the Buffalo/Niagara Falls, New York regions, seeking to reach medically underserved rural and urban Whites, African Americans, and Hispanics, including a growing immigrant and refugee population. Both sites had a need for educational tools in Spanish and English language. The article describes the processes used that uniquely underscore the CBPR foundation of our two CNPCs to produce practical and usable educational tools for introducing a biomedical innovation to diverse members of our respective communities and to measure their impact. Study procedures were approved by the institutional review boards at each institution.

TOOLS AND DEVELOPMENT PROCESS

Purpose and Rationale for the Tools

Each CNPC site independently produced their educational tools on the topic of biobanking fueled by local factors. Prior formative CBPR outcomes from two pilot studies including tours by community members of the Roswell Park Cancer Institute (RPCI) DataBank and BioRepository (DBBR) program had demonstrated that 1) healthy racial/ethnic minority community members had little to no prior knowledge about biospecimen donation or the process involved in collecting and storing biospecimens,[1,11] 2) if potential participants received appropriate information about the process, they were more likely to donate blood to the RPCI DBBR, and 3) community members were more likely to participate if they could donate from community locations, rather than going to the cancer center.[11] Based on these findings, a mobile laboratory van was purchased through an economic development opportunity with New York State to enhance genomic research. Therefore, the community and RPCI required a culturally and linguistically appropriate educational tool that could be used by the outreach team to inform and engage prospective participants at community venues. Developing an educational program using the PowerPoint presentation and the embedded ARS[12,13] questions also helped to facilitate and provide an introduction for the informed consent process for biospecimen donation at community sites. Our WNYC2 team received positive feedback from participants regarding the implementation of the educational program and the efforts made to conduct the research in a community setting as opposed to requiring community members to come to the cancer center.

Specific to TBCCN, community partners expressed interest and enthusiasm to learn about new cancer developments, yet few understood the meaning of the word *biospecimens*, how they were obtained or stored, and how they could actually aid in cancer research. Hence, TBCCN hosted a biobanking presentation and tour of the cancer center's biobank facilities as part of its quarterly community partnership meetings. This collaborative, informative event served as a foundation for the development of the educational tools. Once community members could visualize and lay ‘eyes’ on what a biobank actually looked like, and learn how samples were collected and protected, they developed a greater appreciation about its relevance to cancer prevention and treatment in relation to the future health of their families.

Based on community members’ responses from the biobank tour, TBCCN's central approach for creating the educational tools became centered on introducing the topic from the perspectives of community members, showing images and processes of a biobank along with its quality controls, and addressing critical privacy concerns about biobanking. Adding to this overarching approach, formative research findings from 12 focus groups and 10 provider interviews further informed the developmental process.[14] These data reinforced that visual and print tools were favored by the audience; thus, a toolkit consisting of a DVD and a plain language brochure was developed to prime the public and increase readiness for a biospecimen donation decision if approached in the future.

For both TBCCN and WNYC2, these initial community engagement activities highlighted the public's high interest in learning how biobanking could potentially help future generations.[1,14,15] Therefore, it was decidedly fitting for researchers to thoughtfully involve community members in the educational learning process in a meaningful way, gaining credibility around the topic and dispelling potential “hidden agendas.” The presumption that community members are not interested in complex, scientific cancer topics is a misconception, as one community member shared: “If I don't have information, I don't know what to ask . . . it is simply not on my radar.” Thus, our CNPC teams considered the use of a CBPR approach as a crucial ‘brokerage tool’ to bridge understandings between technology and science and the community, and to better place cancer research innovations on the public's radar.

For both sites, Community Advisory Board members provided their feedback on the methods used to create the tools and offered ongoing critiques as the products moved from draft to final (e.g., format, terminology). Their ideas provided credibility to our tools, making them more responsive to the information needs of our local community members. For both teams, it was important that advisory members felt included and clear about their roles and expectations; for many participants, this was their first time serving as an advisor. Team members (both community and academic) were exposed to a great deal of new technical information. Together, as co-learners, team members deconstructed the information so that a wider net of community members could learn about biobanking. Specific to TBCCN advisory members, a yearly stipend for their contributions was provided. For Roswell, advisory members declined monetary incentives; many were employed and already compensated by their respective institutions outside of this project (this was a decision made by all members). For both projects, advisory members had opportunities to co-author scientific abstracts, presentations, and manuscripts related to the projects as well as attend free capacity trainings (e.g., research, ethics, communications), and had occasions to attend local and national scientific meetings. With this partnership, we hope that our Community Advisory Board members have increased their confidence about communicating information about our projects, and have contributed something substantive to their communities.

Developmental Processes Used by the Teams

Specific CBPR components and iterative developmental processes employed by the two teams are outlined in Table 1. For TBCCN, methodologies reflected systematic steps outlined from NCI's Stages of Health Communication Model,[16] and from the CLEAN (Culture, Literacy, Education, Assessment, and Networking) Look approach that provided underlying frameworks to ensure relevance of the cancer education tools.[8,17] These approaches emphasize methods that engage learners, call attention to the importance of culture and literacy in cancer communications, and reinforce the researcher's ethical duty to provide clear information. The developmental process was further guided by a creative brief, draft outlines, scripts, and storyboards that were vetted continually by our community advisors. Also, a learner–center approach, guided by the work of Doak and colleagues,[18] was used to ensure that the tools were suitable in terms of acceptability, attractiveness, understandability (e.g., language, linguistics, and literacy), self-efficacy, and persuasion. Three rounds of iterations were conducted with a total of 65 community members. Feedback obtained from learner verifications helped to improve the tools' readability, acceptability, layout, and graphics. For example, we incorporated visuals that showed the steps in the collection, processing, and storage of biospecimens; added examples to illustrate the need of biospecimens from healthy community members of diverse backgrounds; and simplified the wording in the booklets.

Similarly, WNYC2 community–academic partners performed an iterative process of presenting and discussing potential concepts, definitions, research examples, photos, ethics concerns, specific biospecimen issues, and the process of donating specimens. Essential content that could be removed was determined collaboratively. An initial draft was compiled from previous formative research findings.[15] Three focus group-like sessions with community stakeholders ensured revisions for relevance, comprehension, clarity and acceptability in three ways: 1) clarity of words and literacy level, 2) local research examples to illustrate the concepts and intent of the research process, and 3) sensitive issues regarding community expectations and research experiences were identified that were extremely useful to prepare DBBR and outreach staff before delivery in the community. The PowerPoint group presentation medium was selected because the community had previous experience with this method; the fact that the slides could be read aloud (in English or Spanish), means that literacy is not a barrier. We had prior data demonstrating acceptability of the tool within the identified priority populations.[3,11,15] The PowerPoint slides included scientific and clinical terms common to biobanking, which were defined and discussed at the program to increase participants' literacy for future interaction with clinical and research opportunities. Figures 1 and 2 provide sample excerpts from both tools, and Table 2 compares the tools at the two sites.

Field Testing of the Tools

The WNYC2 education tool was first field tested with a group of 15 community participants to assess the delivery process to include members of the DBBR staff. This field test resulted in real-time process data that could then be communicated to community stakeholders' and partners during a forum that was held before conducting programs in the community at large. This forum included a scientific panel to answer questions from the community. Feedback from the forum was used to further refine the presentation before delivery in the community. Eleven education programs were conducted in the community with 192 participants (102 African American, 64 Hispanic, 16 other, and 10 no answer) over 7 months. These programs were a part of the iterative process in developing the education tool (i.e., PowerPoint slides in the ARS format) to include feedback from the community participants and were facilitated by a trained health educator. The program was offered in both English and Spanish with a total of eight programs delivered in English and three programs delivered in Spanish.

As a general measure of the impact of the use of the tool in the community, we assessed comparative demographics for participation in the RPCI DBBR. During 2013, when we used the PowerPoint educational program in collaboration with our mobile laboratory van, the DBBR numbers showed an increase of 97% in donations received from minority participants. In 2010, using standard methods within the cancer center, only 5.8% ($n = 74$) of the specimens donated by healthy/noncancer patients were from minority participants. At the end of 2013, after the use of this tool in community settings, 60% ($n = 146$) of all healthy participants were from minority subgroups (30% African American, 23% Hispanic).

TBCCN is currently evaluating the efficacy and impact of DVDs/brochures in English and Spanish on knowledge, attitudes, self-efficacy, and intention to donate to a biobank. The results of these two pilot randomized, controlled trials will guide how the materials will be used, if found to be efficacious. Presently, 69 participants have been enrolled in the English-language pilot and 73 are enrolled in the Spanish-language pilot. As part of this process, the TBCCN team also created an English/Spanish-language instrument, called the BANKS (Biobanking Attitudes and Knowledge Survey) to assess knowledge about, attitudes toward, and self-efficacy regarding biospecimen donation, as reported by Wells et al.[19] For both CNPCs, the full evaluation of knowledge, participant demographics, willingness, and actual and/or intentional biospecimen donation in relationship to exposure to the educational tools will be published upon full completion of the projects.

Using the Tools in the Community

The WNYC2 PowerPoint presentation tool can be used by community health educators, outreach personnel, or volunteers who have been trained in concepts of biospecimen and genomic research, and the ethics and conduct of human research. A maximum of 25 participants is recommended to allow for discussion and interaction from participants in the program audience. On the other hand, the TBCCN toolkit (DVD/brochure) offers flexibility in terms of delivery (e.g., classroom, community outreach events, or one-on-one settings). It can be used as a standalone, priming educational activity in clinics or used to prompt guided dialogue in a classroom setting. The DVD could be used at health events in a group educational session, or as part of a table display (with a small portable DVD player) accompanied by feedback from community health educators to stimulate discussion and questions. Another plausible usage for the tools would be in the recruitment of healthy controls to specific biomolecular research studies. We expect that the educational tools and instruments can be useful to other research teams and/or adapted to other populations (e.g., Asian Americans, Native Americans, or specific Latino subgroups). For example, TBCCN's educational tools have recently been adapted for use with a primarily Puerto Rican population (*Biobanco: Una esperanza de cura para el cáncer)* as part of the Partnerships to Advance Cancer Health Equity project between Moffitt Cancer Center and Ponce School of Medicine.

DISCUSSION/NEXT STEPS

The deployment of community participatory processes that emphasize co-learning resulted in the creation of novel educational communication tools for advancing understandings about genetic and biomedical technologies in an acceptable, engaging, and easy-to-understand manner. In considering the tools, the PowerPoint educational program using ARS can be labor intensive in that it requires staff and volunteers to be trained on cancer genomics and biobanking content. The program requires at least 60 minutes for delivery, including discussion questions from participants. Use of the ARS technology may be a limitation for those that do not own the software or are not familiar with it; however, the content can be adapted to a regular PowerPoint format without the interactive assessments and evaluation that the ARS facilitates. Moreover, the tool can also provide tailored built-in assessments such as intent to participate, demographics, informed consent experiences, and satisfaction/participant feedback. Regarding the DVD/booklet, there is good versatility and convenience with this approach for use with individual (one-on-one) or group education in a variety of clinic, community, or home settings. Further, both the video and booklet could be linked to a website, presented as a podcast, or converted to a mobile app delivered on a smartphone.

In both CNPCs, the tools served both a general educational purpose as well as a specific preparatory instrument for community members who wished to contribute to biospecimen research by donating biospecimens to a biobank. The DVD/brochure and PowerPoint with ARS tools are sensitive to and appropriate for low literacy audiences, and text was written at approximately the grade seven readability level, which is consistent with established recommendations.[20] Each of the tools is available in English and Spanish. In addition, the tools directly address concerns about medical mistrust, examples of historical research exploitation, current policies and protections for research participants, and the importance of biospecimens for future generations, all key themes that emerged from our respective formative work.[1,14,15] Similarly, research in diverse Asian populations have also shown the importance of biospecimen donation for the benefit of future generations.[1,10] The inclusion and consideration of these findings is what uniquely set these materials apart from many other existing tools as well as their focus on noncancer patient communities.

The CBPR process served to broker communication at both institutions among scientists and community members as they became aware of each other's perspectives and biobanking at the cancer centers. Important implications included an increased understanding of methods for introducing innovative biomedical technologies to diverse communities. Moreover, the tools have utility for wider dissemination as interventions to engage the community on biobanking participation and may be most efficacious when paired with a specific research protocol collecting biospecimens or a general institutional biobanking initiative. Further research on the interventional application of the tools is needed to determine efficacy.

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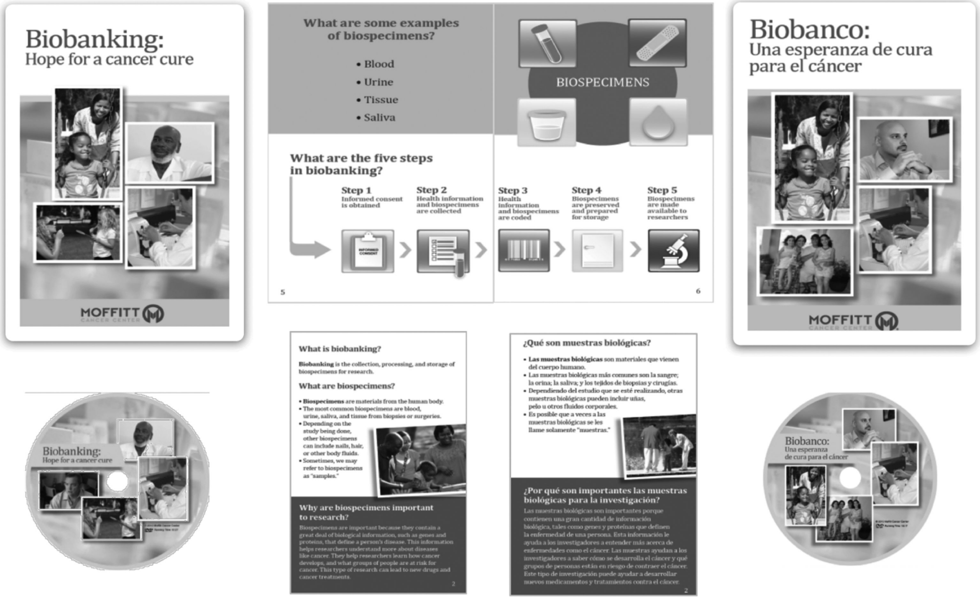


Biobanking:
Hope for a cancer cure

MOFFITT CANCER CENTER

What are some examples of biospecimens?

- Blood
- Urine
- Tissue
- Saliva

BIOSPECIMENS

What are the five steps in biobanking?

Step 1
Informed consent is obtained

Step 2
Health information and biospecimens are collected

Step 3
Health information and biospecimens are coded

Step 4
Biospecimens are preserved and prepared for storage

Step 5
Biospecimens are made available to researchers

5

6

Biobanco:
Una esperanza de cura para el cáncer

MOFFITT CANCER CENTER

Biobanking:
Hope for a cancer cure

What is biobanking?

Biobanking is the collection, processing, and storage of biospecimens for research.

What are biospecimens?

- **Biospecimens** are materials from the human body.
- The most common biospecimens are blood, urine, saliva, and tissue from biopsies or surgeries.
- Depending on the study being done, other biospecimens can include nails, hair, or other body fluids.
- Sometimes, we may refer to biospecimens as "samples."

Why are biospecimens important to research?

Biospecimens are important because they contain a great deal of biological information, such as genes and proteins, that define a person's disease. This information helps researchers understand more about diseases like cancer. They help researchers learn how cancer develops, and what groups of people are at risk for cancer. This type of research can lead to new drugs and cancer treatments.

2

¿Qué son muestras biológicas?

- **Las muestras biológicas** son materiales que vienen del cuerpo humano.
- Las muestras biológicas más comunes son la sangre; la orina; la saliva; y los tejidos de biopsias y cirugías.
- Dependiendo del estudio que se esté realizando, otras muestras biológicas pueden incluir uñas, pelo u otros fluidos corporales.
- Es posible que a veces a las muestras biológicas se les llame solamente "muestras."

¿Por qué son importantes las muestras biológicas para la investigación?

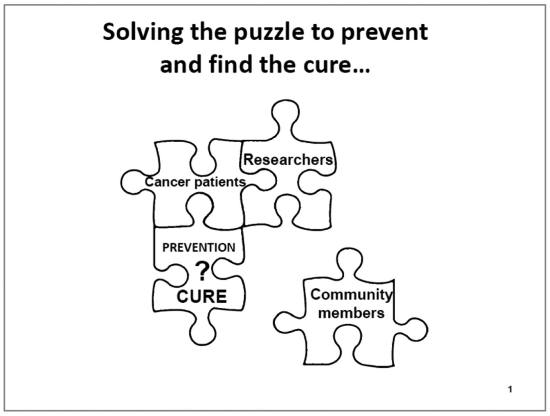
Las muestras biológicas son importantes porque contienen una gran cantidad de información biológica, tales como genes y proteínas que definen la enfermedad de una persona. Esta información le ayuda a los investigadores a entender más acerca de enfermedades como el cáncer. Las muestras ayudan a los investigadores a saber cómo se desarrolla el cáncer y qué grupos de personas están en riesgo de contraer el cáncer. Este tipo de investigación puede ayudar a desarrollar nuevos medicamentos y tratamientos contra el cáncer.

2

Biobanco:
Una esperanza de cura para el cáncer

Figure 1.

DVD and Brochure (English and Spanish) From Tampa Bay Community Cancer Network Site.



Solving the puzzle to prevent and find the cure…

Cancer patients

Researchers

PREVENTION

?

CURE

Community members

Research in action…

Jewels in our Genes Study

To better understand cancer within families

Community Biobanking

- A new research initiative at Roswell Park.
- Involves community-wide participation through voluntary blood donations to the biobank.

EVERYONE needs to be included!

Figure 2.

Examples from PowerPoint presentation at the Western New York Cancer Coalition site.

Table 1

Application of CBPR Process in Tool Development

CBPR Processes	WNYC2	TBCCN
Community engagement and collaboration	• Series of formative studies to discover needs of community members • Biobanking presentation and tour of biobanking facilities at cancer center • Key community stakeholders engaged • Individual community members & small groups asked to convene to discuss & review ideas • Community representatives review & debrief with pilot tools	• Discussion of cancer innovations/new technologies at Community Partner Quarterly Meeting • Biobanking presentation and tour of biobanking facilities at cancer center • Formation of an ethnically diverse and bilingual Biobanking Community Advisory Board (BCAB) that met regularly throughout development process

Use of iterative planning steps	• Formative research consisting of 7 focus groups and 15 Key Informant Interviews with community members (in English and Spanish)
	• Draft ideas with community members and finalize through iterative revisions of tool
	• Step 1: Development of draft content on use of biospecimens in cancer research, donation process, and consent process
	• Step 2: Review draft presentation with community partner groups, and obtain feedback
	• Step 3: Revise tool according to suggestions from the community partners
	• Step 4: Pilot revised tool during community stakeholder forum
	• Step 5: Testing of final drafts in the community
		• Formative research consisted of conduct of 12 focus groups[14] with community members (in English and Spanish language)
		• Learner-centered processes utilized in concept testing and iterative revisions of tools
		• Three rounds of learner verifications were conducted (n=65)
		  • Learner verification step 1: Development of a storyboard, brochure content map, and steps involved in biobanking process
		  • Learner verification step 2: Testing of initial drafts of tools
		  • Learner verification step 3: Testing of final drafts
		• Revisions to tools were made after each iterative round

Conduct and analysis of formative research	• Development of conceptual tool and test willingness to donate biospecimens[3,11,15]	• Development of a creative brief using findings from formative data[14] & BCAB members • Considerations about intended audience and content
Attention to culture and literacy	• Translate version of tools & forms into Spanish • Include local community members in photos used within tool • Include local research projects in tool as examples • Use simple language and give examples • Use of Audience Response System (ARS) to engage community audience in the presentation and facilitate survey process • Community members serve as sources for presentation sites and advise about how presentation is organized	• BCAB members provided feedback on language and cultural appropriateness of content in tools • Include community members in the tools (testimonials, photos) • As English language tools were developed, language considerations were taken for future translation in Spanish (i.e., use of simple terms, development of a glossary of English to Spanish terms, etc.) • Research team worked closely with the director of tissue core operations to simplify scientific terminology, and these terms were later tested in learning verifications iterations with community members
Evaluation and refinement procedures	• Embedded survey questions • Revisions following multiple pilot programs • Spanish language translation and verification • Collection of number & type of participants at programs • Collection of number & type of participants in DataBase & BioRepository (DBBR) • Efficacy of community pilot including implementation of education tool using ARS in conjunction with mobile research lab (in process)	• Learner verifications were conducted with diverse community members, including Spanish-speakers from various Latin American countries to test terminology variations in Spanish dialects. • Interviews tested understanding of key terms, steps involved in biobanking, and overall understanding and acceptability of tools • Pilot RCTs to evaluate the utility of the educational tools and changes in knowledge, attitudes, and intentions to donate (in process)
Identification of public dissemination outlets	• Black & Hispanic newspapers • Radio	• Peer and community dissemination • Community events/conferences • Biobanking tours

Table 2

Similarities and Differences in Development and Focus of the Tools by Site

Components of Tools	WNYC2	TBCCN
Target Audience	• African American • Urban & rural lower income (including White) • Hispanic • “Healthy” lay community members from CNP center catchment area of Buffalo & Niagara Falls, New York regions	• African American • White • Hispanic • “Healthy” lay community members from CNP center's catchment area of Tampa Bay, Florida (Pasco, Hillsborough and Pinellas counties)
Language	• English and Spanish	• English and Spanish
Intended Users	• Research faculty/staff • Community health educators • Used with mobile laboratory	• Community partner groups • Research faculty/staff • Community health educators
Community Input and Ideas	• Request for research examples from local investigators (e.g., Hoy y Mañana), Jewels in Our Genes • Request for examples & photos of local people & programs • Request for basic background on cancer to understand relationship with biobanking • Emphasis on content addressing research injustices.	• Request for information on cancer innovations from community partners • Interest generated through biobank facilities tour • Request for information on how biospecimens could help specific racial/ethnic groups • Emphasis on content addressing research disparities.
Content/ Emphasis	• Lack of minority representation in biospecimen research • Importance of community participation • Addressing research mistrust and concerns • Culturally relevant examples to show that community members have participated in genetic studies • Clarification about difference between biobanking research and medical diagnostics or genetic counseling	• Lack of minority representation in biospecimen research • Importance of community participation • Addressing research mistrust, myths, and concerns (e.g., cloning, access to donated biospecimens, withdrawal of participation, privacy, safety) • Culturally relevant examples regarding wanting to see/hear from cancer survivors about importance of biospecimen research
Format & Length	• PowerPoint Educational Program with embedded survey questions using Audience Response System • 1-hour participation time, including discussion and questions	• Audiovisual toolkit (DVD/brochure) • 11 minute DVD + 12-page brochure • Total time: 23 minutes to view/read materials
Evaluation/Assessment Process	• Embedded survey questions about demographics, knowledge & willingness to participate • Assessment of the number and type of volunteers participating by donating blood and completing epidemiological surveys for the DataBase & BioRepository (DBBr)	• Ongoing learner verification checks • Tools became part of two pilot studies to evaluate efficacy of materials in increasing outcomes, (e.g., knowledge, self-efficacy, attitudes, etc.,) measured by the BANKS[18] • Analysis of pilot projects is under way