



Developing Biospecimen and Clinical Research Education Materials for Ethnic Minorities and Younger Survivors

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Demography of SPA3, Los Angeles

- Los Angeles County is the most populous county in the US. It currently ranks 9th in population when compared to the 50 states, with an estimated population of almost 10 million.¹
- SPA 3 is the 2nd largest SPA in L. A. County, the population is close to 2 million. Close to half of SPA 3's population is Latino (46.4%), 28.2% is Asian/Pacific Islander, 21.6% is white, and 3.7% is African-American, and <1% is American Indian/Alaskan Native.¹
- 23.8% speak Spanish at home, 20.4% speak an Asian language at home. 46.2% of Spanish speakers and 52.4% of Asian/PI Language speakers report speaking English less than "very well."²
- 13.4% of SPA 3 residents have a household income <100% of the Federal Poverty Level. In SPA 3, 24.1% of adults have less than a high school education, while 26.4% of adults have a college or post graduate degree.¹
- About 1 in 3 adults in SPA3 reported difficulties accessing medical care, and over 1 in 4 are uninsured.¹



Biospecimen Banking Clinical Trial Materials and a Video were developed from NCI materials "Providing Your Tissue For Research" and "Donating Tissue for Cancer Research: Biospecimens and Biorepositories" and modifications were made based on input and evaluation of participants.



City of Hope is a Comprehensive Cancer Center as designated by the National Cancer Institute



CCARE collaborates with community organizations to increase cancer prevention and screening, and reduce the burden of cancer.



Administrative Supplement to a grant from the National Cancer Institute to increase research participation of underrepresented groups.

Factors Influencing Biobanking & Clinical Research Participation

- Ethnic minority groups are underrepresented in Clinical (CT) and Biospecimen (BB) research. 17% of all CT participants are ethnic minority.
- Structural, Treating facility, Availability of CT and BB, Quality of care, Cost and Coverage.
- Historical, practical, cultural, and linguistic factors.
- Research staff's cultural and linguistic competency.
- Lack of community inclusion and involvement, and awareness.
- Participants prefer non-invasive biospecimen collection methods.
- Physician and health care team referral and recommendation.

Spanish BB & CT Video

"Para Nuestra Comunidad: Los Estudios de Cáncer" (For Our Community: Cancer Research)

Target Audience: Latino adults age 18-65, male and female. Particularly of interest are those who have a personal or family history of cancer.

Objectives: 1) Increase the number of Latinos who donate BB for medical research and participate in CT; 2) Help individuals understand the importance of BB donation and CT participation; 3) help individuals understand what BB donation is and what entails

Development: Results from previous studies, community assessment and focus groups described a lack of culturally and linguistically appropriate information available to the Latino community regarding BB and CT. Scarcity of videos that addresses BB donation as well as CT. Video is an appropriate media for this population and this issue, particularly low health literacy populations. Script developed and revised based on community consensus and evaluated by community partners.

Creative Considerations: 1) Focus on the benefit for the family and community, collectivistic culture of Latinos; 2) use images of real Latinos, including physician, cancer survivor, donor; 3) video developed in Spanish and script created in Spanish and not simply translated from English version; 4) No images of actual medical procedures or needles or blood so as to not produce fear and anxiety.



Accomplishments & Lessons Learned

- Adopting a broad, multi-level socio-ecological framework to examine, assess, understand and address cancer disparities in our communities
- The community is ready and willing to participate with Comprehensive Cancer Centers (CCC) and health settings to advance their cancer prevention and control work.
- Given that studies demonstrate an association between lack of information and low participation in CT and BB, and that our informative phase and survey participants endorsed interest but rarely attained CT information, we must use multi-level strategies to increase underrepresented population in clinical research
- The NCI-CHE grant enhances the CCC credibility as a source for cancer health disparities experts and resources. Increasing minority participation in CT and BB will take a paradigm shift that includes community providers, community organizations and advocates to inform and navigate persons into research acceptability and participation.
- G/BMaP or NCCCP partner: We are developing our partnerships with our G/BMaP and NCCCP partner, St. Joseph's Hospital Cancer Center in Orange, CA.

Minority Cancer Awareness Week Forum

Activity 3 – Dissemination of NCI-Related Messages, Products and Programs to Researchers and Local Communities

Topic: Putting Research to Action: Charting a New Course for Cancer (2 AMA PRA Category 1 Credits)

Targeted audience: Healthcare Providers, Academicians, Researchers, Grassroots Organizations, Policy Makers and Health Advocates

Total Attendees: 131

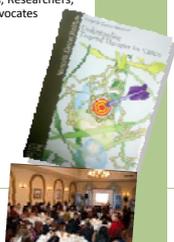
Completed Evaluations: 50

Purposes:

- Discuss disparities in clinical trials, personalized medicine, biospecimen banking, cancer.
- Discuss informational resources available on current clinical trials, personalized medicine, biospecimen banking, and cancer health.
- Identify best practice of increasing minority participation in clinical trials, biospecimen banking, and cancer.
- Outline the various types of cultural diversities (gender, age, race, religion, culture, etc.) that relate to demographics, diagnosis and treatment.

Implications: 92% stated information presented will assist to improve patient care in their research or clinical / work practice. 90% of participants said they intend to make changes or apply what they learned to their research or clinical practice as a result of this event.

Disseminated to over 400 community providers via mass mailing and community events.



Knowledge, Awareness, Acceptability and Participation in Biospecimen Banking (BB) and Research

Activity 1 - Evaluate our BB and CT materials and video to increase awareness and acceptability of BB participation

Targeted Participants: Participants were aged 21 to 63, <45 yrs at diagnosis, 61% were 0-5 yrs post diagnosis

Background: nation-wide sample of 1,473 breast cancer survivors (BCS) conducted by LBCC, one item assessed interest in and attainment of CT materials and resources. LBCC is a national community based organization serving BCS

Methods: Online survey.

Results: 76% endorsed interest in CT. CT interest was also high for ethnic minority respondents (Latina=76%, African-American=79%, and Asian-American=86%), yet only 39% of respondents attained CT information.

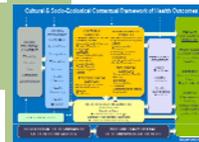
Targeted Participants: Key informant (8 community health leaders) and in-depth advocate, survivor or family interviews with African-, Chinese- and Latino-American participants (n=36)

Background and Methods: We used our local data and existing literature to develop brief, in-language BB and CT educational fliers and for Chinese-, African- and Latino-Americans and 1 video for Latinos. We conducted evaluations with City of Hope researchers and clinicians, community clinicians, community organizations and survivors/advocates.

Results: participants revealed that clinical research acceptability among ethnic minorities is high, yet access to information and resources on CT and BB research is inadequate. Preliminary findings underscored the importance of clear, concise and in-language educational materials.

72% of respondents were confident in their ability to share information about research participation with family after reviewing the materials; 67% were confident in their ability to share with community. 67% were willing to participate in a research study after reviewing the video.

Recommendation: Our participants noted that CT and BB are most acceptable when presented in the contexts of clinical care and doctor recommended. Educational presentations are most effective when conducted by a multidisciplinary team comprising community health leaders (CHL) and scientific and medical experts.



- Effectively distribute NCI and other relevant cancer information to communities in order to enhance decision-making and cancer prevention, screening and early detection practices, as well as coping strategies.
- Provided key input into the development of cancer survivorship care plan and advisories.

Future Directions

- Primary and oncology provider disseminated patient education
- Patient activation via a multi-media campaign about a patients' right to ask about CT and BB. We believe that this multi-level intervention that targets all stakeholders can make improvements in minority representation in clinical, biospecimen and populations research at the local level, and may produce solutions with national applicability.
- Bidirectional communication and training are urgently needed to ready the clinical/medical, scientific and advocacy communities for this new and evolving partnership that engages communities in health care and biomedical research.

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