Biospecimens Education 101: An impact evaluation of a community education curriculum on biospecimen research adapted for six population groups

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I, or an immediate family member, including spouse or partner, have no financial relationship(s) relevant to the content of this CME activity.

The Challenges in Diversity in Biospecimen Research

- Biorepositories are an invaluable resource for basic, epidemiologic, and translational research
- Many public concerns
- Community engaged methods to improve communication and understanding
Cancer Disparities Research Network (CDRN)

Goals of the National Cancer Institute’s Center to Reduce Cancer Health Disparities Geographic Management Program (GMaP) program are:
• Advance the science of cancer health disparities in these regions
• Contribute to the next generation of cancer health disparities researchers
• Achieve measurable reductions in cancer health disparities in these regions

Within CDRN, we focus on:
• Collaborative Research
• Supporting Scholarship
• Communication & Dissemination

CDRN is Region 5 of the NCI’s GMaP Program

Cancer 101 Pilot Project

• Goal: To translate, adapt and evaluate a biospecimen education curriculum for six target population groups: African American, Hispanic, Appalachian, Chinese, South Asian, and Native American.

• Collaborative

• Evidence-based materials
Cancer 101: Modules

- Module 1: Cancer Among Your Target Population
- Module 2: What is Cancer?
- Module 3: Cancer Risk Factors and Risk Reduction
- Module 4: The Role of Genes in Cancer
- Module 5: Cancer Screening and Early Detection
- Module 6: Cancer Diagnosis and Staging
- Module 7: Basics of Cancer Treatment
- **Module 8: Biospecimens and Biobanking**
- Module 9: Chronic Conditions and Cancer
- Module 10: Support for Patients and Caregivers


Cancer 101 Partners

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<tr>
<th>Population Group or Subgroups</th>
<th>Institution Name</th>
<th>Investigator Names</th>
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<tr>
<td>South Asian</td>
<td>Cancer Institute of</td>
<td>Michael Steinberg, PhD</td>
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<td>University of Chicago</td>
<td>Karen Kim, PhD</td>
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<td>Roswell Park Cancer Institute</td>
<td>Deborah Erwin, PhD</td>
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<td>American Indian</td>
<td>Mayo Clinic</td>
<td>Judith Kaur, MD</td>
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<td>Appalachian</td>
<td>Ohio State University</td>
<td>Electra D. Paskett, PhD</td>
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<td>Penn State Hershey</td>
<td>Eugene Lengsner, VMD</td>
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<td>Hispanic</td>
<td>Dana Farber Cancer Institute</td>
<td>Karen Burns White</td>
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<td>U of Chicago</td>
<td>Beth Calhoun, PhD</td>
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<td>Chinese</td>
<td>Memorial Sloan Kettering Cancer C</td>
<td>Francesca Gary, MD, MS;</td>
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<td>Northwestern University</td>
<td>Melissa Simon, MD</td>
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The Process

- Coordinated 11 sites – participation agreements, provided funds to each site
- 11 sites IRB approved
- Developed focus group guide and other materials
- Held focus groups (N=141) to adapt module
- Created core adapted module, slide matrix, resource toolkit
- Six adapted versions completed
- Implementation and Evaluation at 11 sites (N=530)
- Uniform pre-post assessment to allow for cross-site comparison
- Data analysis on Knowledge, Attitude and Intent Change
- Publish results
- Disseminate adapted modules via Cancer 101 website and other venues


Phase 1 - Examples of Adaptations

- Language
- Literacy
- Images
- Video
- Examples
- Narratives
- Resources
- Relevance/Background
Research in Action...

*Jewels in our Genes Study*

- University of Buffalo - A nationwide research study that collects and studies the DNA of African-American women from families with many cases of breast cancer.

- The goal is to find breast cancer genes in African-American women and answer the question of why the disease is more common in some of those families than in others.

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**Phase II - Implementation**

- All sites - standardized
  - Core slides
  - Evaluation questions & protocol
  - Accrual goal
  - IRB approval

- Site specific – adapted
  - Additional slides
  - Length of program & number of programs
  - Types of organizations -- existing relationships
  - Data collection method
Challenges to Implementation

• Fast timelines resulted in extreme variability in data
  – 11 sites, 6 population groups, much variation in age, cancer diagnosis, etc...
  – Race/Ethnicity variability within population groups
• Recruitment Methodology – Convenience
  – Current partners versus new partners
  – Health focus required for some
  – Churches, community groups, veterans groups

Phase II -- Impact Evaluation (N=530)
Demographics

• Mostly female – range from 40%-100%
• Differences by age – across and within populations
• Hispanic ethnicity varied -- Mayo 12%, Rutgers 4%, PSU 6%
• Hispanic sites – 100% on ethnicity, 40% did not answer or preferred not to answer on race
• Not US born –
  • Chinese both sites – 100% no or didn’t answer
  • Hispanic both sites- 14%-36%;
  • SE Asian both sites – 91% - 66%
• Non-English Speaking –
  • Chinese both sites 100% - 86%;
  • Hispanic both sites 76% - 71%;
  • SE Asian (program in English) both sites - 24% -76% other
Phase II -- Impact Evaluation (N~530)

• Cancer & Research Experience
  – Cancer experience varied from 2% - 29%
  – Taken part in research – 5% (UoC) - 28% (Roswell)
  – Donated a specimen – 0% (Northwestern) – 86% (UIC)
  – Family taken part in research – 2% MSKCC – 31% (Mayo)

Attitude & Intent – Pretest Only

• I am worried that donating a sample might hurt or cause health problems for me
  – Ranged from low of 10% at both AA sites to a high of 52% (Rutgers SA) and 55% (Hispanic UIC)

• % of participants who reported they were very likely or somewhat likely to donate a sample to research in the future
  – Ranged from a low of 46% with Native American and Chinese (NU) to a high of 69% with Appalachian (PSU)
Knowledge – Pretest Only

• Composite of four knowledge questions:
  Overall percent of questions answered correctly
  – Ranged from a low of 32% (Hispanic UIC) to a high of 83% (App OSU), 84% (Native American) and 86% (App PSU)
  – All sites got between 71-86% correct.
  – Challenge when designing pre-test

Facilitators and Barriers – Pre/Post

• What would make you more likely to donate a sample to research?
  – #1 rank across almost all sites was “Helping others in the future” both pre and post
• What would make you less likely to donate a sample to research?
  – Lot of variation by site and population group
Lessons Learned

• Committed partners
• Single IRB protocol and materials for tailoring
• Translation challenges
• Recruitment variability – balance of fit & fidelity
• Common themes and recommendations
  – Lots of lively discussion and questions, need knowledgeable trainers
  – Interest in donation – be prepared to offer next steps (on site or other)
  – “If you’re not at the table, you’re on the table.” – RP volunteer

Future Research Questions

• Use Cancer 101 to enhance the consent process
• Implement the program to measure:
  – Willingness to donate
  – Behavior outcomes (blood, spit, etc...)
  – Comparison of donation rate by method (on-site or elsewhere, immediate or delayed)
  – Comparison of donation rate by other demographics
    • Race/ethnicity, age, experience with cancer or other disease
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• Northwestern University
• Mayo Clinic

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