#### Use of Perceptual Mapping to Encourage Informed Decision Making on Clinical Trials in African American Cancer Patients



Sarah Bauerle Bass, Ph.D., MPH; Linda Fleisher, Ph.D., MPH; Armenta Washington, MS; Andrea Nicholson, MPH; Laurie Maurer, MA, Ph.D(c); Daniel Geynisman, MD



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#### Sarah Bass and Linda Fleisher, PIs



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# Background

- Minority populations participate in clinical research at lower rates than whites, despite carrying a disproportionate load of the cancer burden. <sup>1,2</sup>
- Up to 20% of minority cancer patients are eligible to participate in clinical research, yet only 3-5% do.<sup>1</sup>
- Previous studies have classified barriers to participation as protocol-related, patient-related, or physicianrelated.<sup>3</sup>

<sup>1.</sup> Comis R. L., & Crowley J. (2006). Baseline study of patient accrual onto publicly sponsored U.S. cancer clinical trials: An analysis conducted for the Global Access Project of the National Patient Advocate Foundation. Coalition of Cancer Cooperative Groups: Philadelphia.

<sup>2.</sup> Siegel, R., Naishadham, D., & Jemal, A. (2013). Cancer statistics, 2013. A Cancer Journal for Clinicians, 63(1), 11-30.

<sup>3.</sup> Education Network to Advance Cancer Clinical Trials (ENACCT) and Community-Campus Partnerships for Health (CCPH). (2008). Communities as Partners in Cancer Clinical Trials: Changing Research, Practice and Policy. Silver Spring, MD



## **Research Focus**

Although barriers to participation in research among African American and other minority populations have been explored, limited research has focused on comparing the unique perceptions of those who do and do not participate in clinical trials.



## Purpose

- Use perceptual mapping techniques to determine perceived facilitators and barriers to clinical research participation in African American cancer patients.
- 2. Use results to guide development of a mobile application decision-aid .

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# **Study Design**

**Phase 1:** In-depth discussions with African American cancer patients who have and have not participated in clinical trials, to elicit barriers to and facilitators of participation and validate which are most critical to the patient population.

<u>Phase 2:</u> Develop and administer the perceptual mapping survey instrument to inform message foci of decision aid.

<u>**Phase 3:</u>** Develop a multi-media mobile application decision aid, and conduct usability testing with patients and providers.</u>

#### Perceptual Mapping and Vector Modeling Methods







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#### Q: How can I see inside someone's mind?

# By measuring & mapping how they associate elements with each other.

(as distances)



## Methodology – Perceptual Mapping

- Perceptual mapping uses multidimensional scaling (MDS) and message vector modeling techniques -often used in marketing research.
- The models are three-dimensional and display how respondents perceive the relationships among a set of elements (e.g. risks & benefits). Provides insights into decision-making for diverse populations.
- Resulting map reflects how the elements are conceptualized relative to each other and relative to "Self," an aggregate group average.



# **Mapping Method**

- Use traditional surveys
- Respondents not required to abstractly think about how concepts are or are not related to each other, which makes the method easy to use in populations with all literacy and cognitive abilities.
- The maps provide a snapshot of the respondents' conceptualization of the situation, and reveal the relative importance of different elements.

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## **The Measurement Process**

#### Mental association—judged as distance (0-10) "0" = strongly disagree "10" = strongly agree

#### How much would you agree that:

I know where to get information about clinical trials.\_\_\_\_\_
Being part of a clinical trial can give a person a sense of purpose in life.\_\_\_\_\_



# **Mapping Analysis**

- **COGNIPLOT**, computer software developed at the RCL, is used to create the perceptual maps.
- The program converts the scaled judgments (through a scalar-products procedure) into inter-point distances used in the mapping.
- Associations among the questionnaire elements are derived from the inter-item correlations of all elements, where the absolute values of the Pearson product-moment correlations are converted to a 0-10 scale.

#### **Resulting Map**



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## Vector Modeling – Creating the "Message"

- Used to "move" the person/group to the preferred location in the perceptual map by identifying the target vector (i.e. participate in a clinical trial). Push/pull like a physics model.
- By specifying the target vector and the number of concepts to be used in the final message, the software creates all possible vector resolutions, and rank orders the solutions for best fit to the target vector.
- The "best fit" solution is then evaluated for conceptual consistency and practical utility.

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## Application – Not the "Kitchen Sink"

- The message is designed to include and illustrate the concepts that are identified as critical for addressing the target population's concerns, knowledge, and perceptions of risks-benefits for that particular decision.
- This procedure allows us to accurately tailor the decision aid directly to the target population's conceptualization of the risks and/or benefits of carrying out the hoped for behavior or decision.
- Issues that are not perceived as being important are not included, thereby allowing the message to focus on only the concepts that will "move" the group toward the desired location in the conceptual space.

## **Vector Modeling - Example**



#### Phase II – Survey and Analysis





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## Phase II – Study Methods

Forty-one (41) English speaking African American patients at least 21 years of age were recruited from two cancer centers in Philadelphia.

Eligibility included:

- Group 1: <u>Have participated</u> in a clinical trial within the last 9 months or were willing to participate but were found to be ineligible
- Group 2: <u>Have not</u> participated in a clinical trial due to either refusing or never being offered a trial
- An in-person or over-the-phone questionnaire was administered that included demographics and assessed factors that influence clinical trial knowledge, perceptions, and participation.



# Demographics

**Mean age:** 60 (SD 12.6) **Gender:** 51.2% Female Clinical Trial Status: 36.6% had participated; 53.7% had not; 9.8% were "confused" (these 4 people were not included in the perceptual mapping analysis) Education: 39% HS grad; 39% some college or college grad **Cancer Diagnosis:** 61% diagnosed in last two years; 24% prostate, 12% breast; 12% colorectal, but 12 types represented. 75% first time.

## Overall Beliefs about Medical Care Not Participated



## Overall Beliefs about Medical Care Participated



#### Sources of Support and Self-Efficacy Not Participated



## Sources of Support and Self-Efficacy Participated



## Value of Clinical Trials Not Participated



## Value of Clinical Trials Participated



## Knowledge of Clinical Trials Not Participated



## Knowledge of Clinical Trials Participated



## Reasons to Decide to Participate Not Participated



## Reasons to Decide to Participate Participated



## Reasons to Not Participate Not Participated



# Reasons to Not Participate Participated



#### Main Messages to Emphasize in Intervention

**Six Themes** 

- 1. I'm not sure why it is important for me to be in a clinical trial.
- 2. I'm not sure that clinical trials fit with my beliefs about how to treat my cancer.
- 3. I'm not sure I would want to be part of a clinical trial.
- 4. I'm not sure what a clinical trial is.
- 5. I'm not sure how to find information on clinical trials.
- 6. I'm not sure why I would decide to be in a clinical trial.

**Theme 1 emphasize**: what CTs are and how they have informed current treatments

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**Theme 2 emphasize**: CTs are another treatment option to explore, similar to home remedies.

**Theme 3 emphasize**: normal to be unsure about being in CT and have fears; important to talk with doctor and family about a big decision.

Theme 4 emphasize: all types of things we use every day are products of research; provide basic info about CTs.

Theme 5 emphasize: Many ways to get more information, where to get info

Theme 6 emphasize: Higher purpose of participating in CTs; importance of making right choice for patient

#### **Development of mychoice mobile app**







#### I'm not sure how to find information on clinical trials.



#### I'm not sure that clinical trials fit with my beliefs about how to treat my cancer.



#### • You might feel there is a benefit to using home remedies and alternative medicines when you feel sick. As long as you talk to your doctor, many of these are fine to continue while receiving cancer treatment. In addition to taking vitamins or other things you normally do to stay healthy, remember that the best way to take care

of your health is to consider all treatment options. including clinical trials.

How would I benefit from being in a clinical trial?

 $(\checkmark)(\mathbf{X})$ 

How am I helping others in my family or my community if I take part in a clinical trial?

"Ouestions to Talk with Your Doctor About"

Now you will see a series of questions that many patients have about participating in clinical trials. If you would like to talk with your doctor about a question, tap the green checkmark. If the question is not something you'd like to talk to your doctor about, tap the red x. After you've gone through

all the questions, those you are interested in will appear at the end. You can then show these to your doctor to help focus on what is most important

to you. You will also have the option to have more information printed or emailed to you to read later.

How do I benefit if I choose to be part of a clinical trial?





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## **Conclusions and Implications for Research**

Perceptual mapping and vector modeling methods can elucidate message strategies to encourage clinical trial participation and clearly show how to effectively address barriers to clinical trial participation.

<u>**Research Implications:**</u> Using these methods to compare barriers in African American patients in those who have and have not participated is novel and provides a more targeted strategy to develop interventions.

<u>**Clinical Implications:**</u> Spending time discussing the clinical trial process, addressing negative perceptions of clinical trials and promoting their benefits would be more beneficial for African American patients to make an informed decision about participation, rather than interventions focusing on mistrust.



## **Thank You!**

#### Sarah Bauerle Bass, Ph.D., MPH 215-204-5110 sbass@temple.edu

#### Linda Fleisher, Ph.D., MPH 267-426-3191 FleisherL@email.chop.edu

