

Assessing the impact of health literacy, numeracy and race on willingness to participate in biomedical research

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MEHARRY
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ALLIANCE

SINCE 1999

What is the CDRN?

- ▶ **Clinical Data Research Network**
- ▶ Vanderbilt University Medical Center received award from Patient-Centered Outcomes Research Institute (PCORI) to establish *Mid-South CDRN*
- ▶ PCORI funded 11 CDRNs and 18 Patient-Powered Research Networks (PPRNs) in its first cycle
 - ▶ As of now, there are 13 CDRNs and 20 PPRNs making up a National Patient-Centered Clinical Research Network (PCORnet)
- ▶ **Goals:**
 - ▶ To help us improve how we deliver health care and the quality of care we deliver in a **patient-centered manner**



Mid-South CDRN Program Overview



Mid-South CDRN Stakeholder Engagement Strategy (Phase I)

Activities for Stakeholder Engagement

Method	Target	Method Description
Patient Investigator	1	Integral part of the research team
Governance	10	Oversight Committee-2, Stakeholder Engagement Council (Advisory Council)-8
Community Engagement Studios	75-90	Patients from VUMC, VHAN, Meharry, Matthew Walker Center and the Greenway PRIME network
Clinician Interviews	100	Semi-structured interviews with clinicians
Clinician Surveys	500	Targeting clinicians less engaged with research
Patient and Community Surveys	5,000	Web-based and in-person surveys of patient and family stakeholders from CDRN hospitals and practices

Background - What does the literature tell us?

- ▶ Limited health literacy & numeracy **reduces** patient's understanding & application of health information
- ▶ **Little is known** about the impact of these variables on participation in research

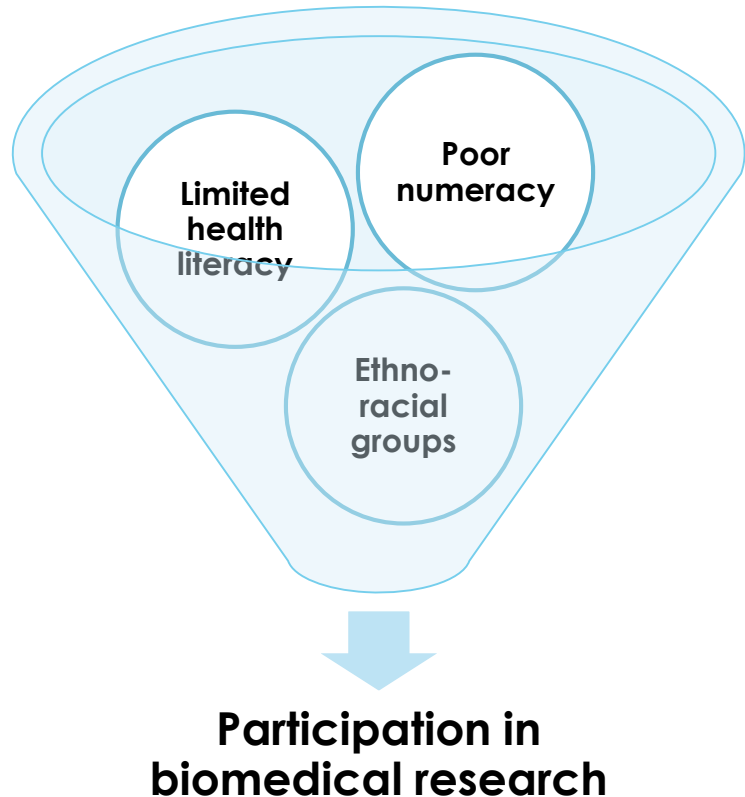
Complex informed consents/research protocols

+

highly technical language

=

may limit willingness to participate in research (particularly groups who are underrepresented in research)



Recruitment strategies



researchmatch



MEHARRY[®]
MEDICAL COLLEGE

VANDERBILT UNIVERSITY

As of right now there are:

volunteers

83,307

researchers

3,264

studies

430

institutions

111



MATTHEW WALKER
Comprehensive Health Center, Inc.



Objective & Demographics

► Objective:

- To determine whether health literacy and numeracy are associated with willingness to participate in biomedical research

Table 1. Study of Participants Demographics (n=3,756)

Gender	Male	Female	
	30.1%	69.2%	
Age, years	18-45	46-64	65+
	41.2%	37.1%	14%
Race	Caucasian	African-American	
	80.8%	14.6%	
Income	<\$49 999	\$50 000+	
	37.4%	52.1%	
Education	Some high school (HS)	HS graduate/Some college	College graduate+
	2.6%	37.3%	59.5%

Demographics	Technology	Research Experience
Year of birth	Cell phone access	Asked to participate
Marital status	Texting	Research participation and description
Education	Internet access	Preferred method of contact
Employment	Computer confidence	Level of participation interest in 7 different types of studies
Gender	Health Literacy	Health information sources
Ethnicity	Confidence in understanding medical forms	Trust
Race	Assistance reading hospital materials	Level of trust of health information from a list of 9 types of sources
Doctor visit	Understanding written information	A 12-item scale developed by either Hall et al. or Mainous et al. measuring Trust in medical research
Clinic visit	Numeracy	Barriers to Participation
Long term health conditions	Fractions	11 items to determine level of agreement or disagreement with statements regarding research participation
Household income	Percentages	Selection of types of barriers considered with participating in research
Health insurance	Usefulness of numerical information	Precision Medicine
CLINICAL DATA RESEARCH NETWORK (CDRN) VARIABLES		Familiarity with the following phrases: Genetic Testing, Biomarkers, Precision Medicine, and Pharmacogenetics
		Importance of individual's health and genetic privacy

Scales used in Survey Data Collection

► Survey Content:

- 78 items containing 8 sections including:
 - Brief Health Literacy Screen (BHLS)¹
 - Subjective Numeracy Scale (SNS-3)²
 - Seven questions regarding willingness to participate in research

Willingness to participate in Biomedical Research

Completing a survey ≥ 2 times

Giving a blood sample

Taking part in a study by phone or internet

...7-item survey

Questions were scored 1 through 3. 1 representing "Not interested"

Health Literacy

How confident are you filling out medical forms by yourself?

How often do you have someone help you read hospital materials?

... 3-item scale

Questions were scored 1 through 5 using a Likert scale. 5 representing "Not at all".

Numeracy

How good are you at working with fractions?

How good are you at figuring out how much a shirt will cost if it is 25% off?

... 3-item-scale

¹ Cavanaugh, K., Osborn, C., Tentori, F., Rothman, R., Ilkizler, T., & Wallston, K. (2015). Performance of a brief survey to assess health literacy in patients receiving hemodialysis. *Clin Kidney J.*, 8(4), 462-468. doi:10.1093/ckj/sfv037

² McNaughton, CD., Cavanaugh, KL., Kripalani, S., Rothman, RL., Wallston, KA. (2015). Validation of a short, 3-Item version of the subjective numeracy scale. *Med Decis Making.*, 35(8)932-6. doi:10.1177/0272989X15581800

Methodology

► Exclusion criteria:

- Respondents that did not fully complete:

- BHLS
- SNS-3 or
- Willingness to participate in biomedical research questions.

► Analysis:

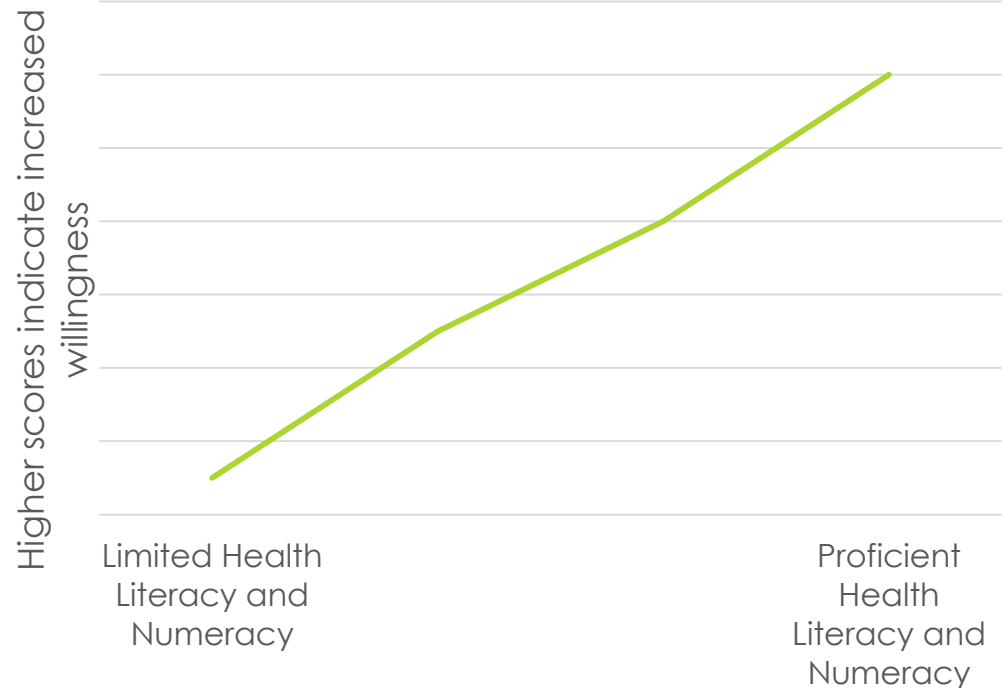
- Hierarchical linear regressions used to analyze effect of health literacy, numeracy & race on willingness to participate in biomedical research.

Table 2. Study of Analysis Cohort (N=3046)

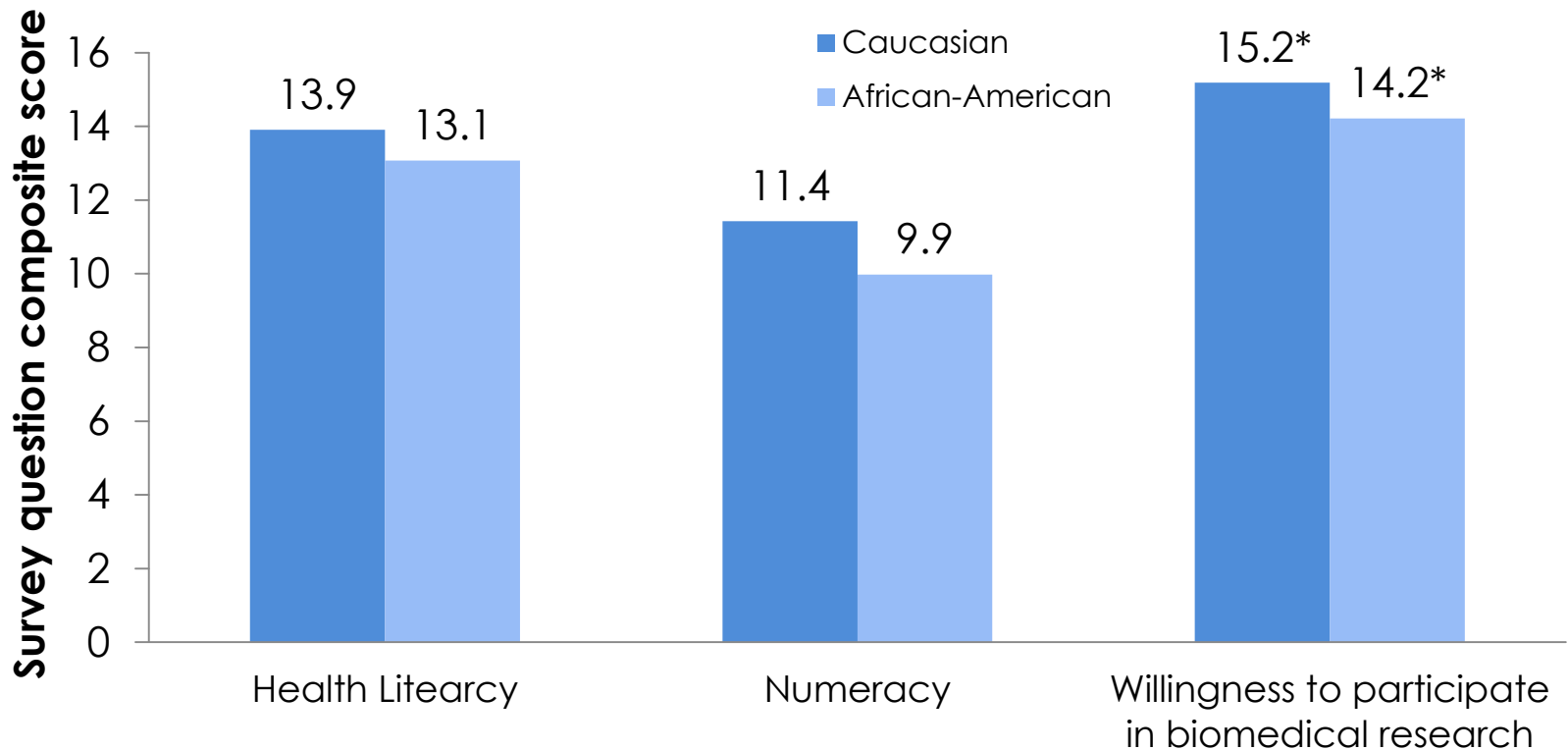
Sex	Male	Female
	34%	66%
Race	Caucasian	African-American
	73.3%	17.3%
Age	Mean age	
	47.9 years	

Willingness to participate in biomedical research is influenced by health literacy

- ▶ Those with lower health literacy were **less** willing to participate in biomedical research (**$p < 0.001$**)
- ▶ Those with a lower numeracy were **less** willing to participate in biomedical research (**$p < 0.001$**)



The influence of race on survey scales



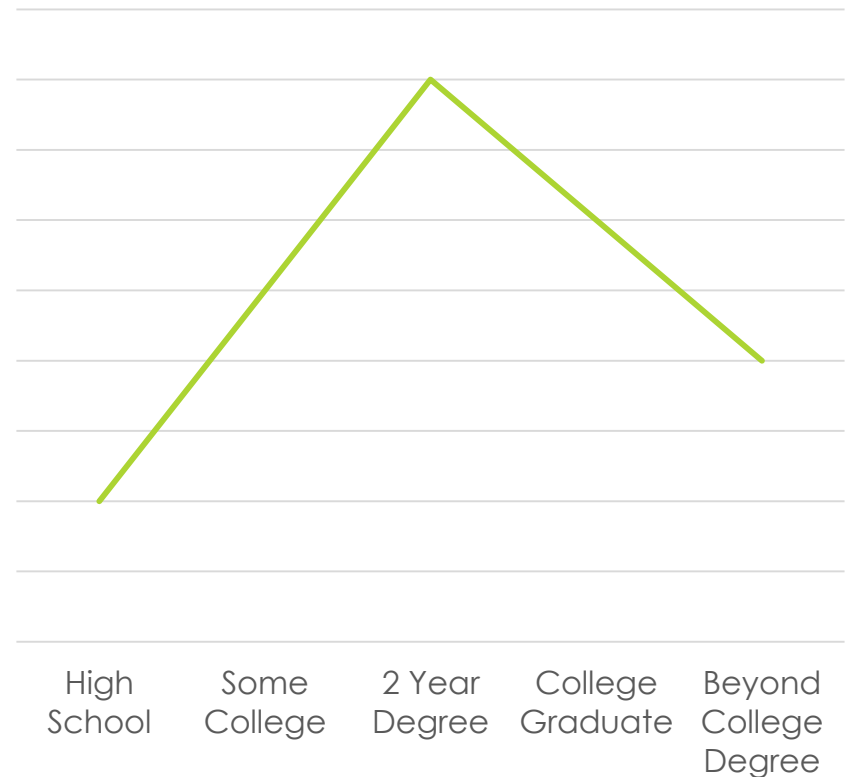
Higher scores indicate higher health literacy and numeracy & more willingness

*** Indicate significant results with a ($p < 0.001$)**

Is willingness to participate affected by education?

- ▶ Educational attainment, positively correlated with willingness to participate in research among those with some college, a 2-year degree or less
- ▶ Willingness to participate in biomedical research **did not** correlate at higher levels of education (college graduates and beyond)
- ▶ **What does this mean for future research?**

Higher scores indicate increased willingness



Conclusions & Future Directions

- ▶ Health literacy and numeracy **are associated** with willingness to participate in biomedical research
- ▶ This is one of the first studies to show this association
- ▶ Complex **consent forms** may be impeding the ability of those with limited health literacy from participating
- ▶ Next steps would be to administer literacy tests before recruiting patients to design literate-appropriate research documents

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Patient-Centered Outcomes Research Institute