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INTRODUCTION

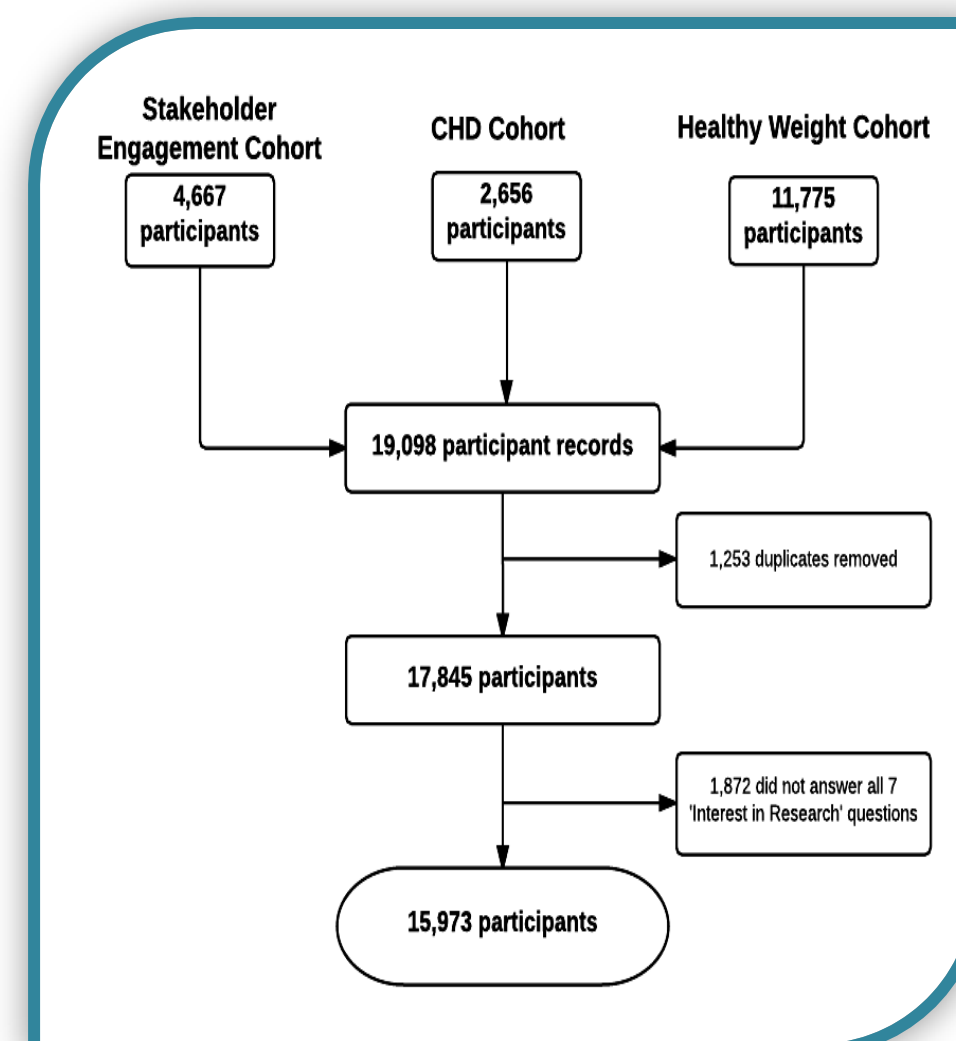
- Individuals' participation in research is related to their age, race, gender, education, and income
- Less attention has been given to the influence of health literacy and numeracy skills
- We examined the independent association of patients' health literacy and numeracy with their interest in research participation

METHODS

- **Setting**
 - The Mid-South Clinical Data Research Network (CDRN), funded by the Patient Centered Outcomes Research Institute (PCORI), includes three large health systems: Vanderbilt Health System, Vanderbilt Healthcare Affiliated Network (VHAN), and Greenway Health
- **Subjects and study design**
 - Patients from the CDRN were identified and enrolled into one of the following groups: Coronary Heart Disease (CHD) cohort, Healthy Weight (HW) cohort, or Stakeholder Engagement (SE) cohort
 - All three cohorts used a cross-sectional study design, administering online surveys one time per participant
- **Measures**
 - Health Literacy and numeracy were assessed using the validated, 3-item, Brief Health Literacy Screen (BHLS) and Subjective Numeracy Scale (SNS), respectively
 - The outcome was a 7-item instrument assessing participants' interest in different types of research, including taking surveys, giving a blood sample, participating via phone/internet, meeting at local community centers, involving family, and staying overnight at a hospital. The index demonstrated high internal consistency reliability (Cronbach's alpha=.86).
 - The response scale ranged from 1 ("Not Interested") to 3 ("Very Interested") and a summary score was computed by adding all seven questions together to create a scale from 7 to 21, where higher score indicate more interest in research participation overall
- **Analysis**
 - Linear regression models determined characteristics independently associated with patients' willingness to participate in research studies

RESULTS

Figure 1. Study flow diagram



- Data were pooled from 3 large surveys conducted by the Mid-South CDRN, with a total of 15,973 unique participants

Table 2: Distribution of interest by research study type (N=15,973)

	Not Interested	Somewhat Interested	Very Interested
Complete survey 2 or more times	7.1%	39.5%	53.3%
Give a blood sample	17.9%	44.8%	37.2%
Complete survey via phone or internet	16.3%	43.6%	40.0%
Take a medication	43.2%	42.2%	14.5%
Meet at community center or school	41.2%	43.0%	15.7%
Enroll in a study involving people in your family	37.9%	45.4%	16.5%
Stay overnight at hospital	50.4%	37.4%	12.1%

- As burden on the individual increases the interest level in participating in research studies decreases (i.e. driving to another location or staying overnight at a hospital)

Table 1: Patient characteristics (N=15,973)

Participant Characteristics	N (%) or Mean (SD)
Age, mean (SD)	52.86 (16.5)
Health literacy (BHLS), mean (SD)	13.5 (2.1)
Numeracy (SNS), mean (SD)	14.3 (3.6)
Participated in previous research	
Yes	4,823 (32.4)
No	10,057 (68.0)
Household density, mean (SD)	2.4 (1.2)
Gender	
Female	10,199 (65.5)
Male	5,380 (34.5)
Race/Ethnicity	
White	12,827 (81.3)
Black	1,675 (10.6)
Hispanic	286 (1.8)
Native American	243 (1.5)
Asian	248 (1.6)
Other	65 (0.41)
Multi-racial	424 (2.7)
Income	
Less than \$10,000	631 (4.5)
\$10,000 to \$19,999	1,081 (7.7)
\$20,000 to \$34,999	1,904 (13.6)
\$35,000 to \$49,999	2,032 (14.5)
\$50,000 to \$74,999	2,883 (20.5)
\$75,000 to \$99,999	2,139 (15.2)
\$100,000 or more	3,376 (24.0)
Education	
Less than high school	489 (3.1)
High school degree	2,213 (14.2)
Some college or 2-year degree	4,448 (28.6)
College graduate	3,898 (25.1)
More than a college degree	4,512 (29.0)
Employment	
Employed	8,907 (55.9)
Unemployed	767 (4.8)
Retired	3,528 (22.1)
Unable to work (disabled)	1,394 (8.8)
Other	1,333 (8.4)
Marital Status	
Married/ Living with partner	10,938 (69.0)
Widowed	860 (5.4)
Divorced/ Separated	1,986 (12.5)
Never married	2,075 (13.1)

- Participants were predominately female (65.5%), White (81.3%), around 52.8 (SD±16.5) years old, and had relatively good health literacy (M=13.5 (SD ± 2.1)) and numeracy (M=14.3 (SD ± 3.6)) skills

RESULTS - CONTINUED

Table 3. Predictors of interest in research participation

Patient characteristic	Adjusted β (95% CI)
Age	-0.005 (-.011, .000)*
Health literacy (BHLS)	0.140 (.108, .171)**
Numeracy (SNS)	0.106 (.088, .125)**
Previous research, Yes	1.206 (1.080, 1.332)**
Race/Ethnicity	
White	Ref
Black	-.079 (-.276, .117)
Hispanic	.306 (-.113, .725)
Native American	.359 (-.093, .810)
Asian	-.748 (-1.195, -.301)*
Other	.316 (-.374, 1.007)
Multi-Racial	.042 (-.838, .921)
Education	
Less than high school	-0.337 (-.720, .046)
High school graduate	-0.249 (-.456, -.042)*
Some college/2-year degree	0.410 (.251, .570)**
College degree	0.039 (-.115, .194)
More than a college degree	Ref

Linear regression model: also controlled for income, marital status, and employment which were significantly associated in unadjusted analysis

- Participants who were younger, had prior research participation, and higher health literacy and numeracy skills were more interested in participating in research studies

CONCLUSIONS

- Limitations: Data were obtained from participants that had responded to the survey (i.e. research). The study design was cross-sectional, therefore a causal relationship cannot be determined
- After controlling for demographic factors, participants with higher health literacy and numeracy skills were more interested in participating in research studies
- Prior research participation does influence participants' interest in participating in future studies
- Additional work is needed to elucidate reasons for this finding and to determine strategies to engage these vulnerable populations

ACKNOWLEDGEMENTS

Supported by awards: CDRN-1306-04869 (Mid-South Clinical Data Research Network - Patient Centered Outcomes Research Institute (PCORI)) and VICTR UL1 TR000445 from NCATS/NIH (REDCap)