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BACKGROUND

- Racial/ethnic minority participation in research, particularly genetic research, is lower than whites
- Lack of representation prevents translation of genetic research to reduce racial/ethnic disparities in health outcomes.

OBJECTIVES

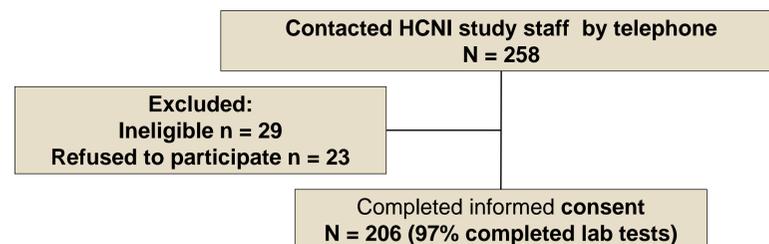
- Using partnered methods, we assessed willingness to share specimens and data for research in a community-based sample of African American (AA) and Latino residents in a low income community of South Los Angeles.

METHODS

Recruitment and Data Collection

- The **Healthy Community Neighborhood Initiative (HCNI)**, a multifaceted community partnered participatory research (CPPR) study to build community trust and increase research participation while improving health and health care in a predominantly African American and Latino community in South Los Angeles.
- Eligible adult residents participated in a 2-hour in-home interview, clinical evaluation, laboratory and functional tests.
- Informed Consent.** Participants were asked for approval to allow investigators to:
 - Store their de-identified data for future use,
 - Obtain additional DNA for research purposes, and
 - Share their samples with other researchers
- Participants were also asked for approval to:
 - Share the results of the examination with their personal physician.

Figure 1: Sample Derivation



Analysis

- Constructed a composite score of the number of willingness to share questions to which a participant consented (range: 0 – 3)
- Analyzed the question on consenting to share results with personal physician separately as a dichotomous variable
- Bivariate tests of association between demographic characteristics and chronic conditions by race/ethnicity
- Bivariate tests of association between demographic characteristics and chronic conditions by a) composite willingness to share score and b) willingness to share results with physician
- Multivariable models: a) ordered logistic regression models for the composite score and b) logistic regression models for the willingness to share with the physician

RESULTS

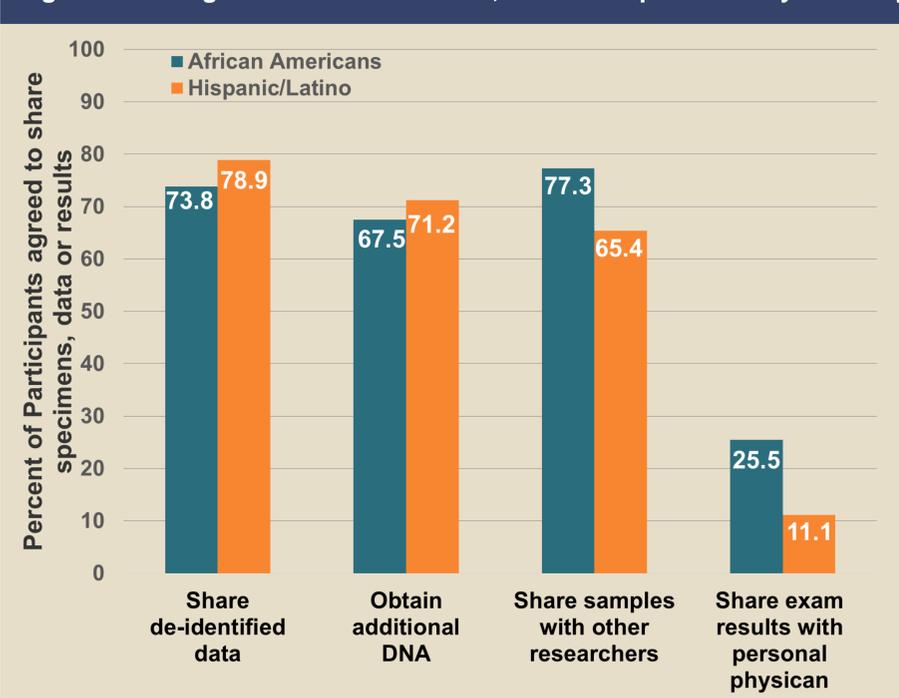
Table 1: Demographic and Chronic Conditions (n = 206)

	African American (n = 154)	Hispanic/Latino (n = 52)	P-value
Age, years, mean (SD)	46.9 (16.1)	38.3 (14.4)	0.001
Male, n (%)	45 (29.2)	15 (28.9)	0.96
Spanish language survey, n (%)	0 (0.0)	38 (73.1)	-
Education:			<0.0001
Less than high school	23 (14.9)	25 (42.3)	
High school or GED	19 (12.3)	12 (23.1)	
Any post-high school education	112 (72.7)	15 (28.8)	
Health insurance	113 (74.8)	18 (34.6)	<0.0001
Usual source of care	137 (88.9)	35 (67.3)	0.0003
Self-rated health very good or excellent	44 (28.6)	10 (19.2)	0.18
Chronic Conditions:			
Hypertension	68 (44.2)	9 (20.9)	0.006
Asthma	26 (16.9)	2 (3.9)	0.02
Diabetes	25 (16.2)	3 (5.8)	0.06
Osteoarthritis	46 (29.9)	10 (19.2)	0.14

Table 2: Multivariate Models of Willingness to Share Data and Specimens

	Willingness to share data and specimens with other researchers (ordered logistic regression)		Share results with personal physician (logistic regression)	
	Odds ratio (95% CI)	p-value	Odds ratio (95% CI)	p-value
Age	1.00 (0.98 – 1.02)	0.94	0.98 (0.96 – 0.99)	0.03
African American (ref: Latino)	0.96 (0.47 – 1.95)	0.91	1.11 (0.45 – 2.75)	0.81
Education (ref: < high school)				
High school graduate or GED	1.29 (0.57 – 2.94)	0.53	0.76 (0.31 – 1.83)	0.53
Post high school education	0.87 (0.42 – 1.84)	0.72	0.60 (0.25 – 1.45)	0.26
Health insurance	0.52 (0.28 – 0.98)	0.04	1.39 (0.63 – 3.01)	0.42
Self-rated health very good or excellent (ref: Poor/Fair/Good)	0.84 (0.45 – 1.54)	0.57	0.48 (0.24 – 0.96)	0.04
Activities limited because of physical or emotional problems	2.06 (1.01 – 4.17)	0.05	1.37 (0.56 – 3.36)	0.48
Number of chronic conditions	1.03 (0.73 – 1.56)	0.87	1.21 (0.79 – 1.84)	0.38

Figure 2: Willingness to Share Results, Data and Specimens by Ethnicity



The study was approved by the CDU IRB and registered by the UCLA CTSI
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CONCLUSIONS

- In this community partnered project, African Americans and Latinos were generally willing to share results, data, and specimens with researchers and have their de-identified data stored for future studies
- Rates of consent to share/store data/specimens did not differ by ethnicity.
- Participants with health insurance were less likely to consent to sharing data and specimens, while participants with activity limitations were more likely to consent.
- Low rates of consent to share results with personal physicians may be due to *low realized access to care* (despite reporting high levels of usual source of care) or, among Latinos, language barriers with their personal physicians (73% of Latino participants completed the study in Spanish)

LIMITATIONS

- Small geographic area in South L. A. that may not be generalizable to other communities
- Small sample size
- Self-reported chronic conditions may have been under reported

POLICY IMPLICATIONS

- Research studies collecting genetic and biomarker information in minority populations may benefit from community partnered approaches to increase the likelihood of minority participation