

# TRIBAL COMMUNITY WILLINGNESS TO PARTICIPATE IN GENETIC RESEARCH AND RECOMMENDATION 5

WHAT ABOUT PRIVACY AND PROGRESS IN WHOLE GENOME SEQUENCING  
GENETIC ALLIANCE WEBINAR SERIES  
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*DATA FROM*

ENGAGING AMERICAN INDIAN  
COMMUNITIES IN RESEARCH THROUGH  
COMMUNITY-BASED SYSTEM  
DEVELOPMENT

FUNDING FROM NHGRI CHALLENGE GRANT RC1 MD 004304

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# Vignettes

## Behavioral Study

- ◆ RCT to test how changes in behavior affect health
- ◆ Tx group: 5 weekly 1-hour support group sessions
- ◆ Control group: informational materials only
- ◆ 4 research visits over 6 months for participants in both groups
- ◆ All the study visits and treatments provided free of charge

## Genetics Study

- ◆ Case-control study to see if certain genes contribute to health
- ◆ Participation involves being interviewed about health and giving blood
- ◆ Data collection for the study will take about 2 hours



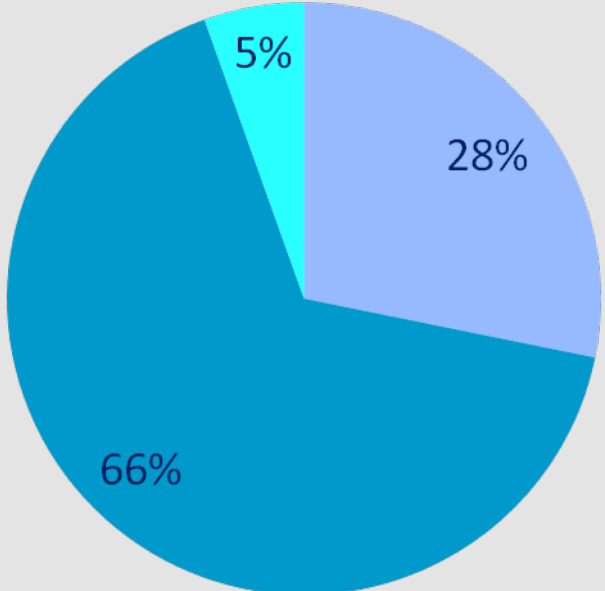
# Survey

- For each vignette, we went through 8 “what if” scenarios to evaluate how the different factors might change willingness to participate in the research
  - 1.If conducted by a college or university
  - 2.If conducted by the Indian Health Service (IHS)
  - 3.If conducted by the federal government (not IHS)
  - 4.If community members were involved in developing the study
  - 5.If the study were approved by the Tribe
  - 6.If community members were involved in data collection
  - 7.If community members were involved in data interpretation
  - 8.If the focus of the study were on diabetes
- Also asked about the best place within the Tribal organization to house a new research oversight committee



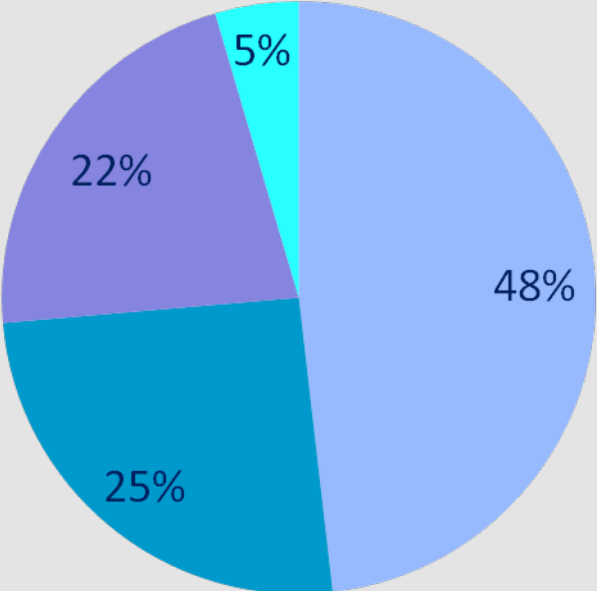
# Participants: 110 Tribal Members

## Gender



- Male
- Female
- NA

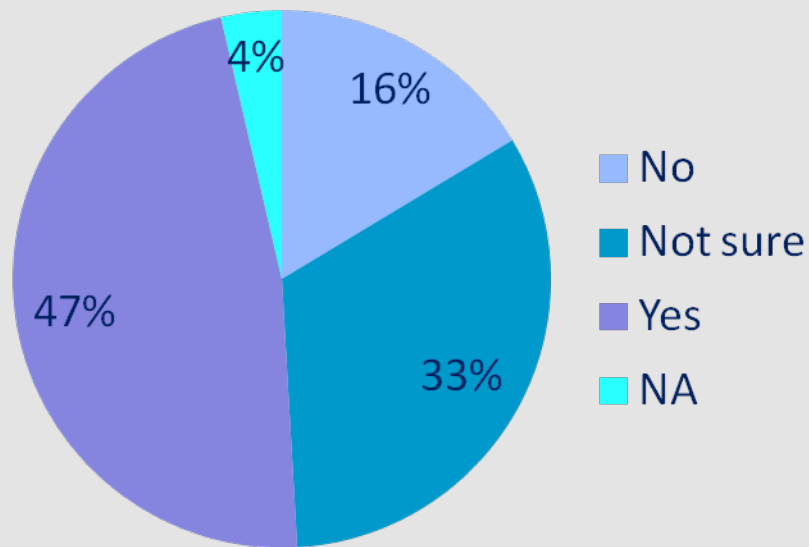
## Age



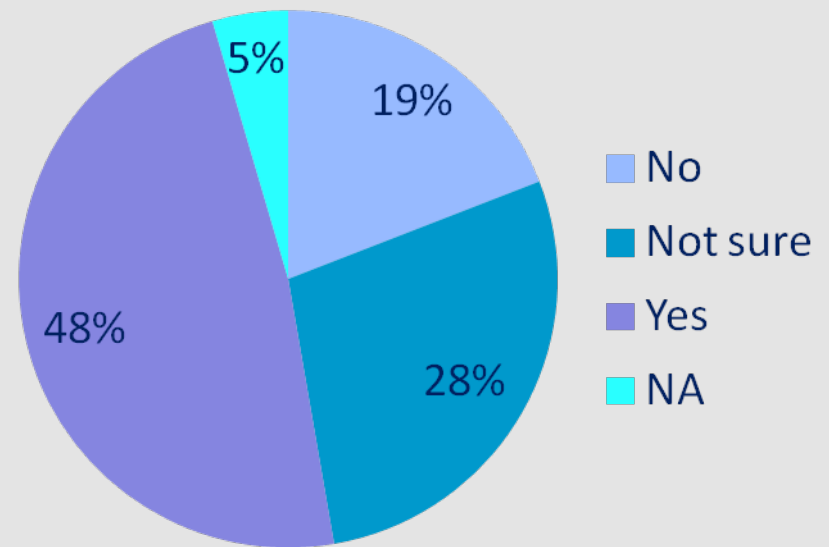
- 18-39
- 40-54
- 55+
- NA

# Willingness to participate

## Behavioral Study



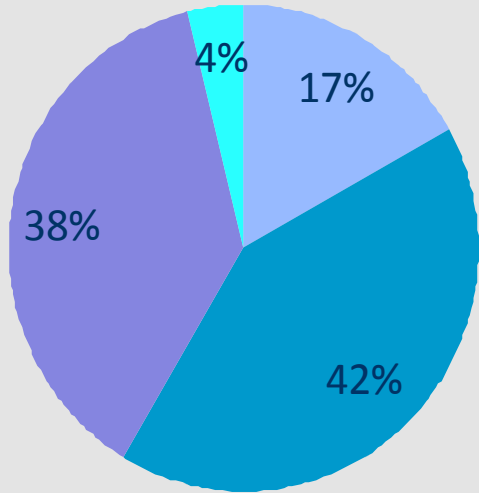
## Genetics Study



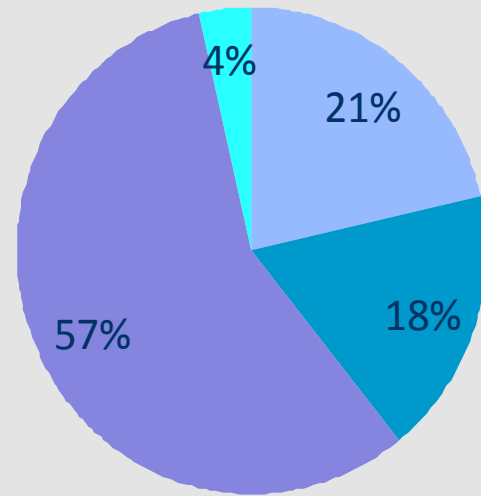
No differences between study types;  $P=0.77$

# Genetics study by age

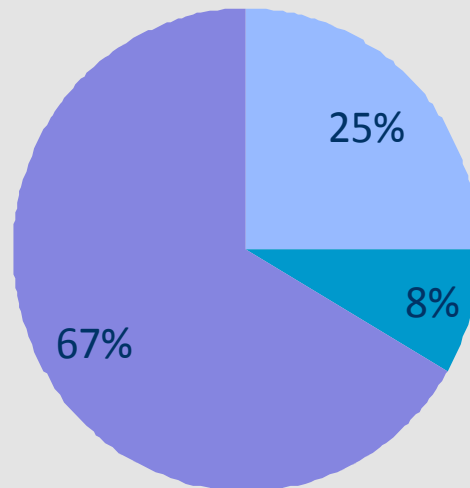
**18-39 (n=53)**



**40-54 (n=28)**



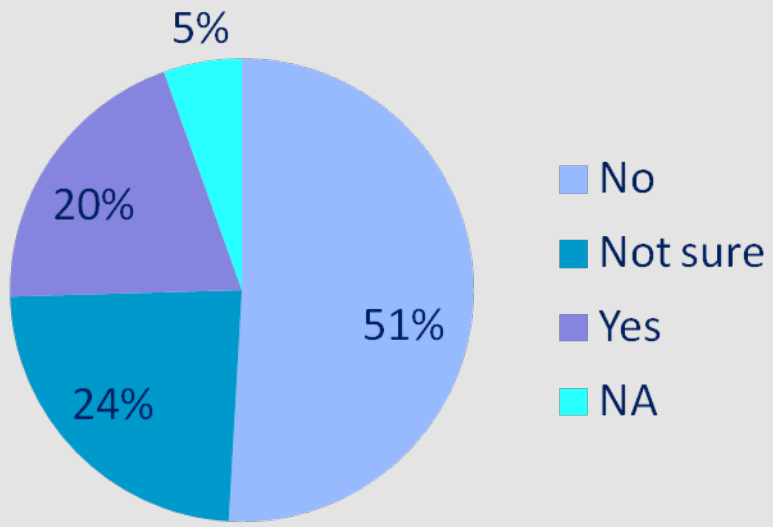
**55+ (n=24)**



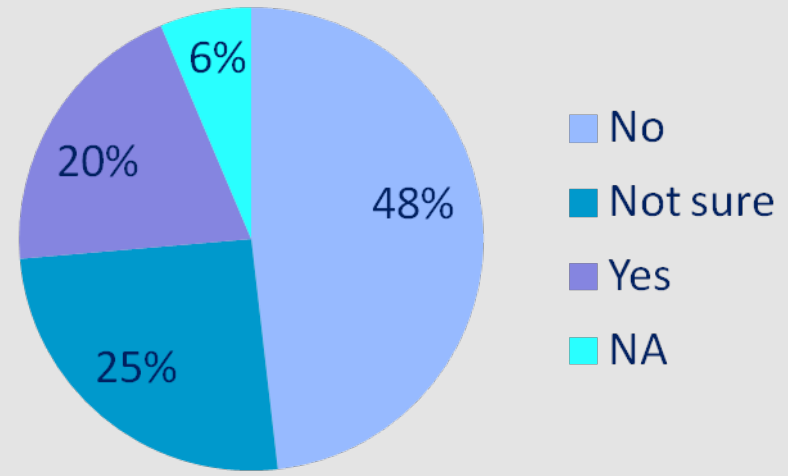
Differences by age; P=0.05

# If Conducted by Federal Govt (not IHS)

## Behavioral Study



## Genetics Study

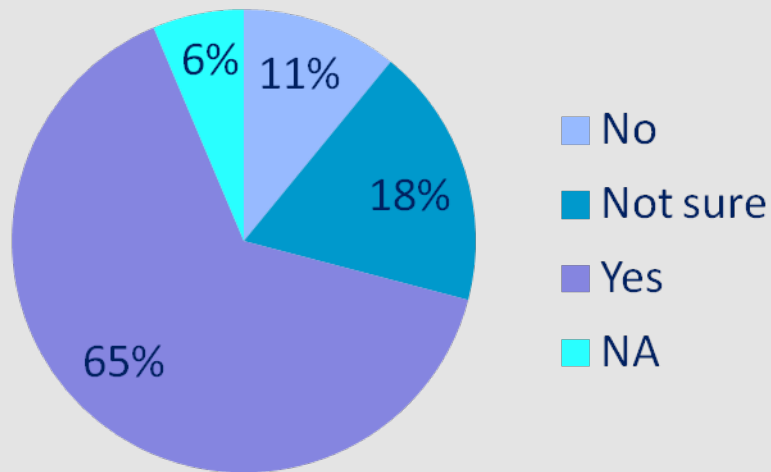


No differences between study types; P=0.98

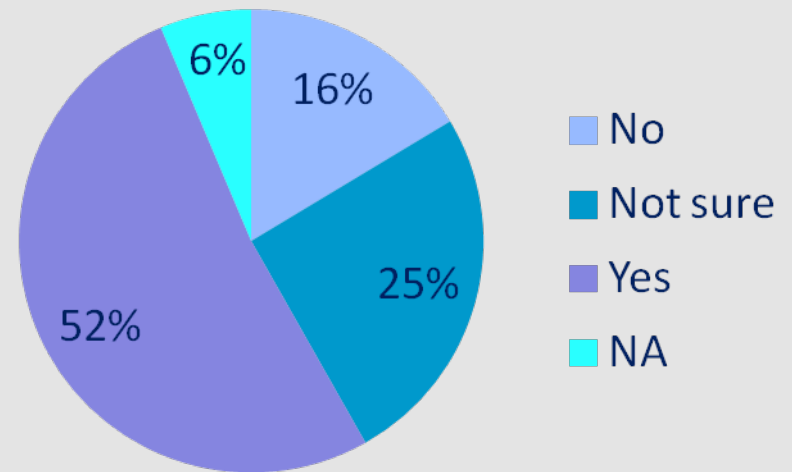


# Community Involvement w/Study Development

## Behavioral Study



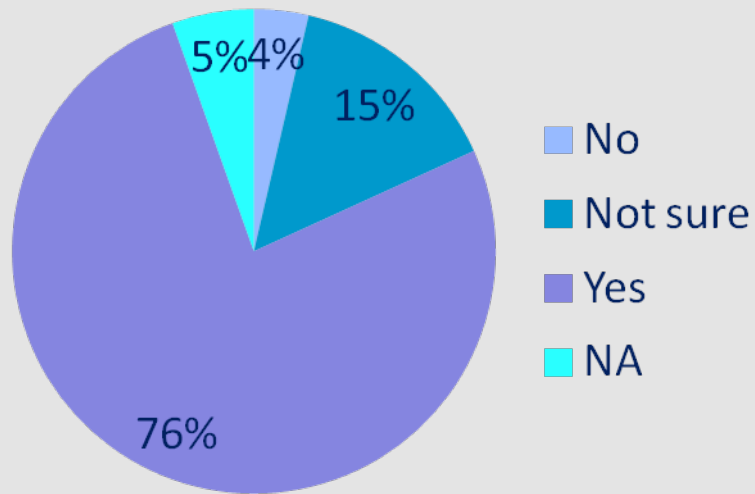
## Genetics Study



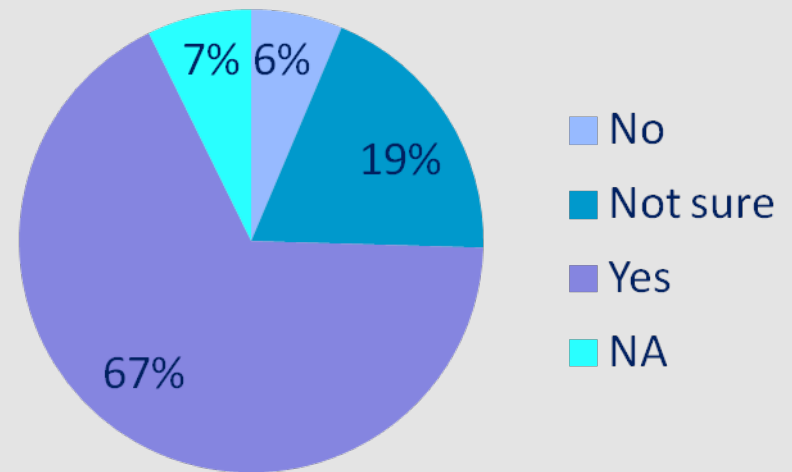
No differences between study types; P=0.15

# Diabetes is Focus of Study

## Behavioral Study



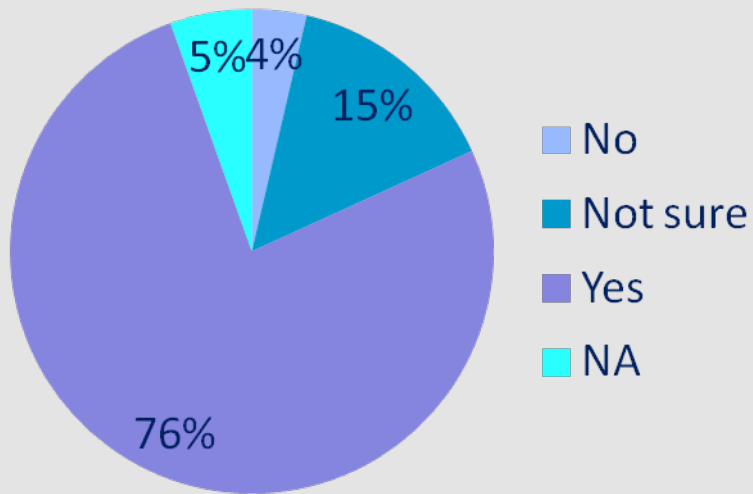
## Genetics Study



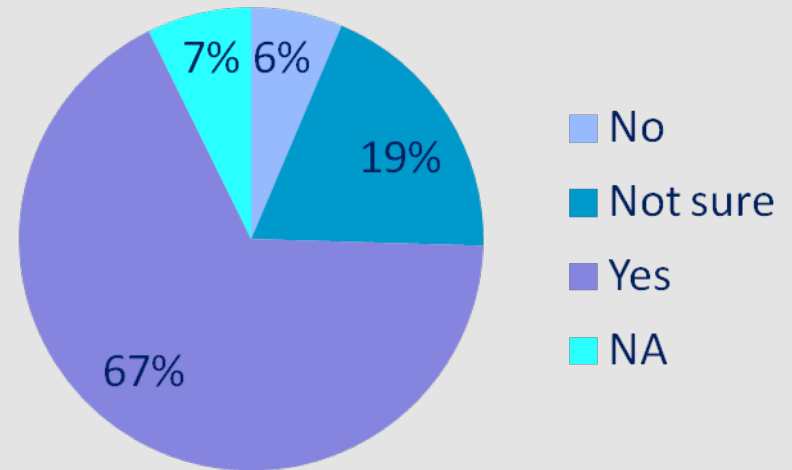
No differences between study types; P=0.30

# Diabetes is Focus of Study

## Behavioral Study



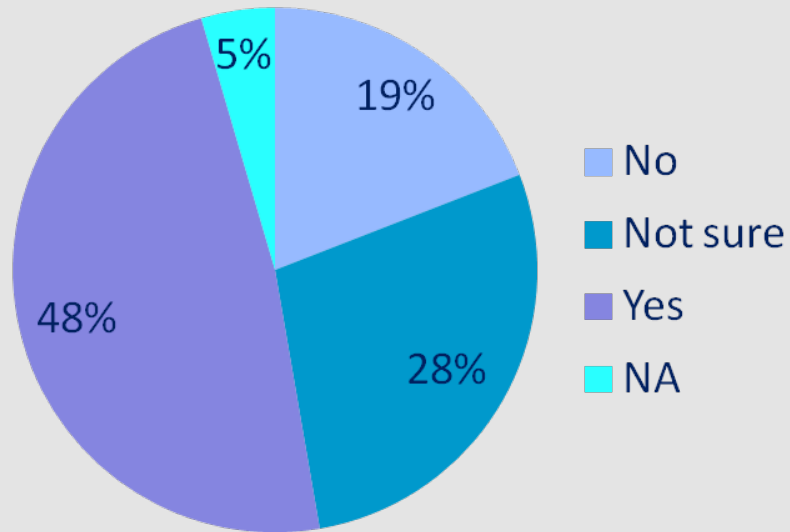
## Genetics Study



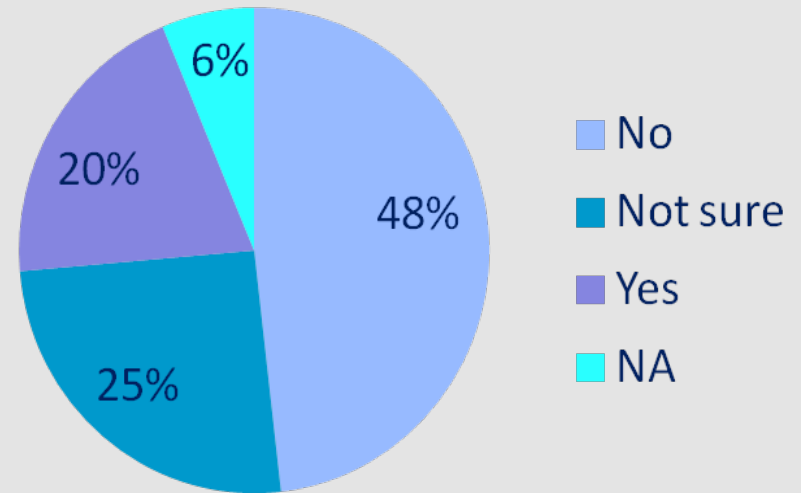
No differences between study types; P=0.30

# General Willingness vs. Federal Gov't

## General Willingness



## Federal Gov't



# Thank You!



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