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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Engaging American Indian Communities in Research Through Community-based System Development

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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: 66%
- Female: 28%
- NA: 5%

**Age**
- 18-39: 48%
- 40-54: 25%
- 55+: 22%
- NA: 5%
Willingness to participate

Behavioral Study
- No: 47%
- Not sure: 33%
- Yes: 16%
- NA: 4%

Genetics Study
- No: 48%
- Not sure: 28%
- Yes: 19%
- NA: 5%

No differences between study types; P=0.77
Genetics study by age

18-39 (n=53)

- Yes: 42%
- Not sure: 4%
- No: 17%
- NA: 38%

40-54 (n=28)

- Yes: 57%
- Not sure: 4%
- No: 18%
- NA: 21%

55+ (n=24)

- Yes: 67%
- Not sure: 8%
- No: 25%
- NA: 6%

Differences by age; P=0.05
If Conducted by Federal Govt (not IHS)

Behavioral Study

- No: 51%
- Not sure: 24%
- Yes: 20%
- NA: 5%

Genetics Study

- No: 48%
- Not sure: 25%
- Yes: 20%
- NA: 6%

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

- 76% No
- 15% Not sure
- 4% Yes
- 5% NA

Genetics Study

- 67% No
- 19% Not sure
- 6% Yes
- 7% NA

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**
- No: 48%
- Not sure: 28%
- Yes: 19%
- NA: 5%

**Federal Gov’t**
- No: 48%
- Not sure: 25%
- Yes: 20%
- NA: 6%
Thank You!