

# Participation in Clinical Research: A Thorough Explanation in Their Own Language Helps Family Medicine Patients Decide.

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# Participation in Clinical Research:

## *What Influences Primary Care Patients?*

**Melanie B. Johnson MPA**

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# Disclosure of Commercial Relationship(s)

**None of the authors listed below have any financial relationship to disclose.**

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- Charity Curtis, MPH
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# Lehigh Valley (LV) PBRN



- Supported by Lehigh Valley Health Network
- Established 2003
- 800,000 people in primary service area
- 250 primary care physicians
- 90 practices
- Diverse ownership models

# Background

- **Enrollment in Clinical Research is difficult in almost all areas of medicine.**
- **FDA guideline recommending sex-specific analyses.**
- **Women and under-served populations are under-represented in clinical research, despite improvements.**

# Objective

**To identify factors that influence  
primary care patients'  
participation in clinical research.**

# Methods

- **A validated, anonymous 44- question IRB approved survey in four primary care practices.**
- **Offered in English, Spanish, Traditional Chinese and Simplified Chinese.**
- **Autonomous patients  $\geq 18$  years of age**



# Hypotheses

- **Patients with higher education and socioeconomic status are more open to participate.**
- **Distrust in doctors plays a major role in preventing patient participation.**
- **Patients would be more likely to participate if additional resources were made available.**

# Limitations

- Interim analysis
- Selection bias
- Convenience sample
- Incomplete surveys

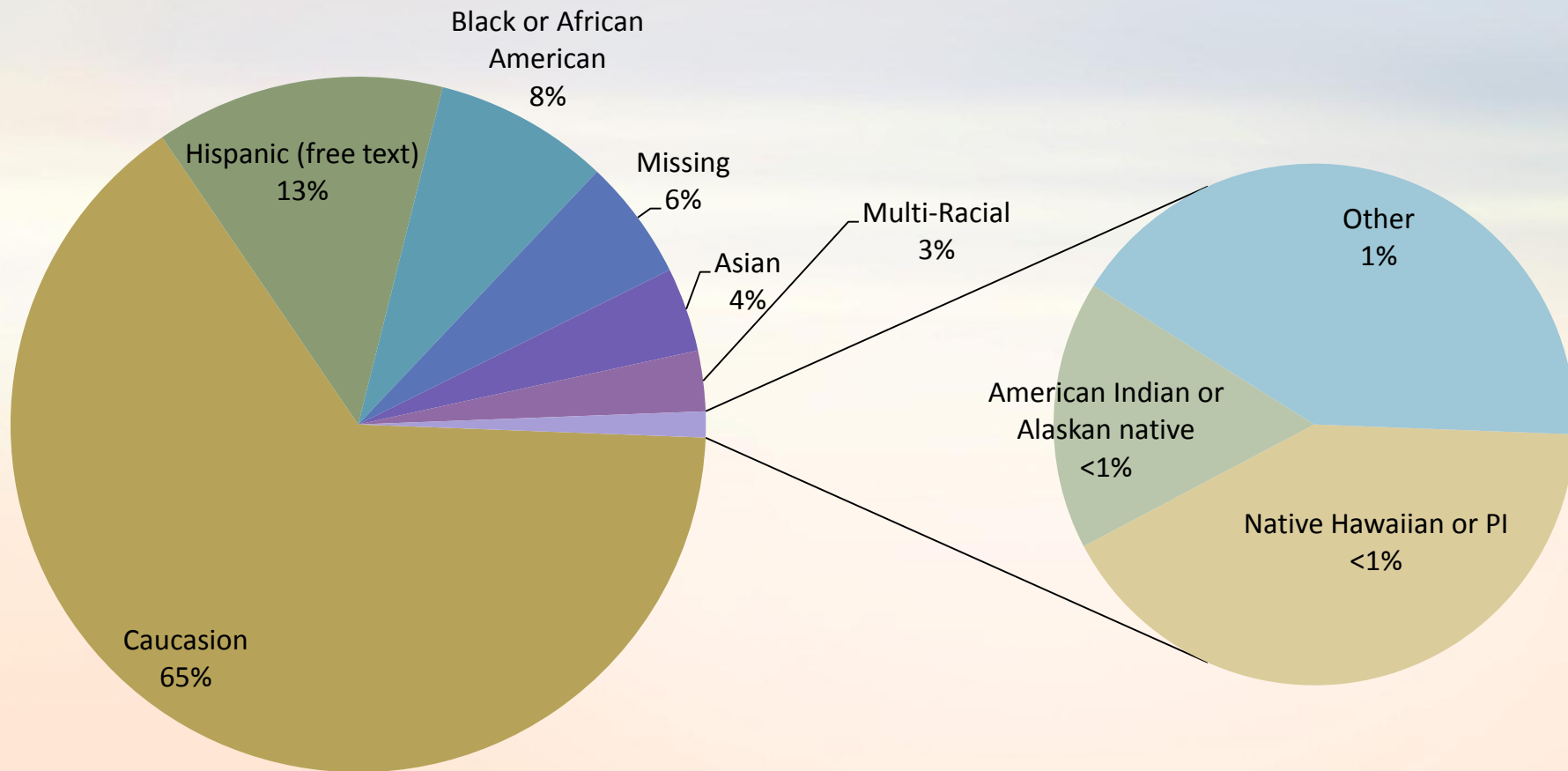
# Interim Analysis Method

- **Comparisons made by Fisher's Exact test and Chi-square, as appropriate.**
- **Logistic regression analysis to compare levels of education and income to participation.**

# Participants

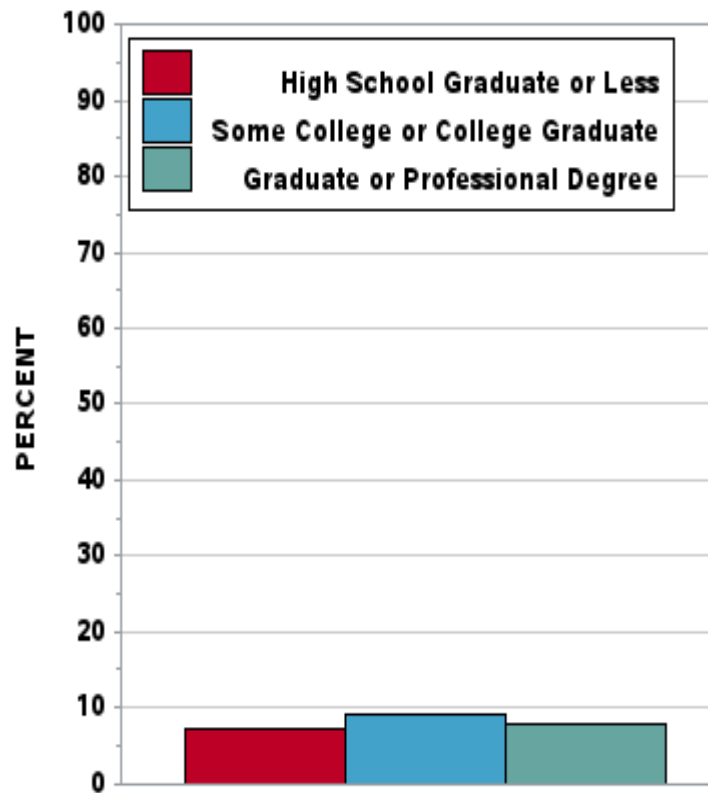
- N= 432
- 70% female
- 91% had not participated in prior clinical research

# Participant-Reported Demographics

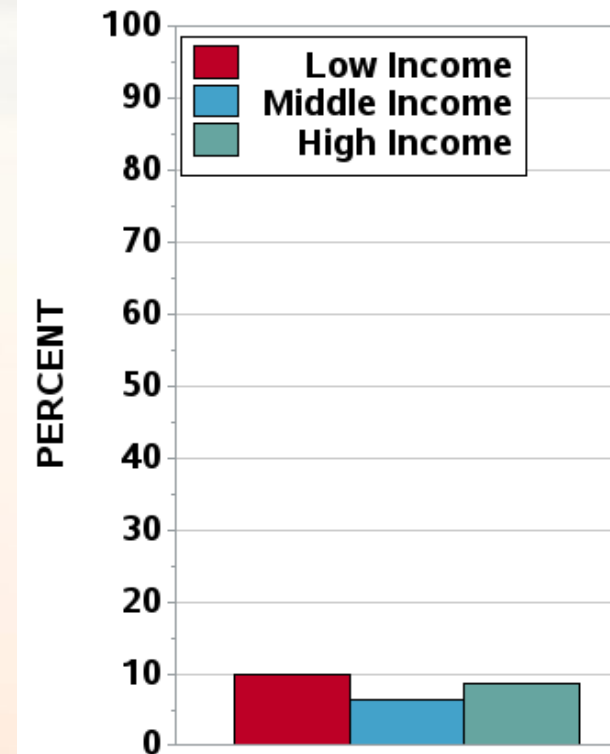


# Prior Research Participation

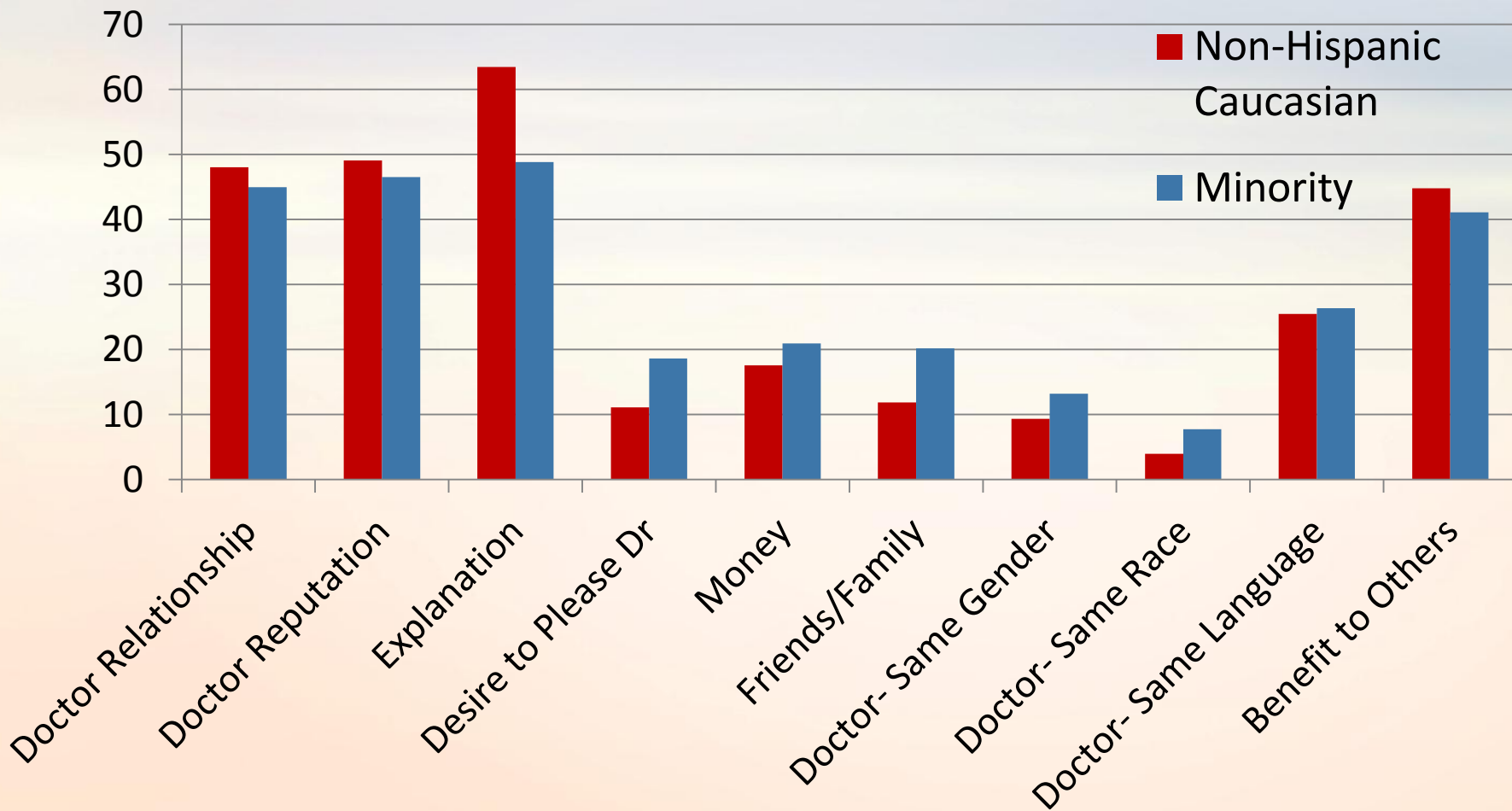
## Education Distribution



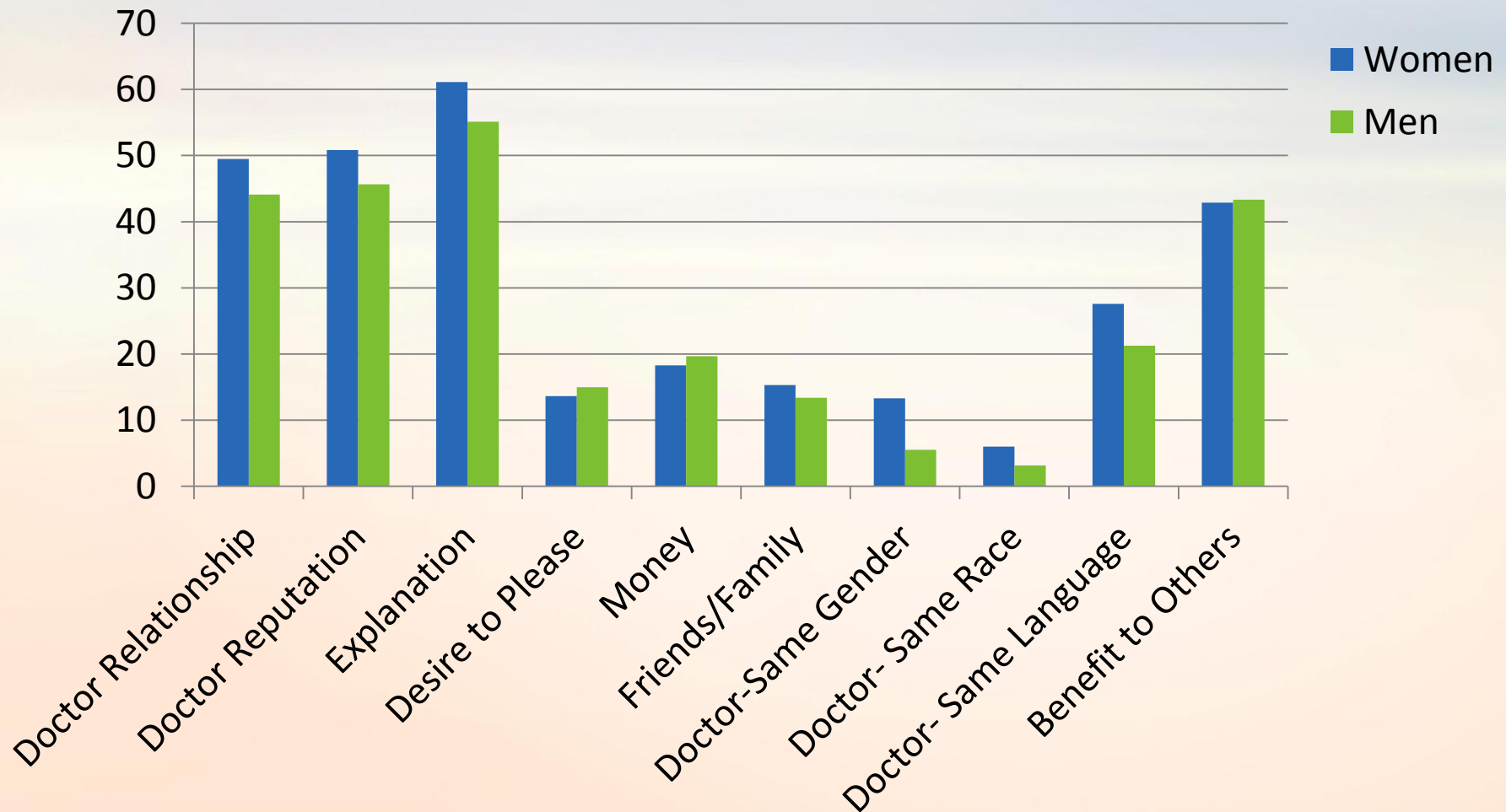
## Income Distribution



# Motivators to Research Participation- Race

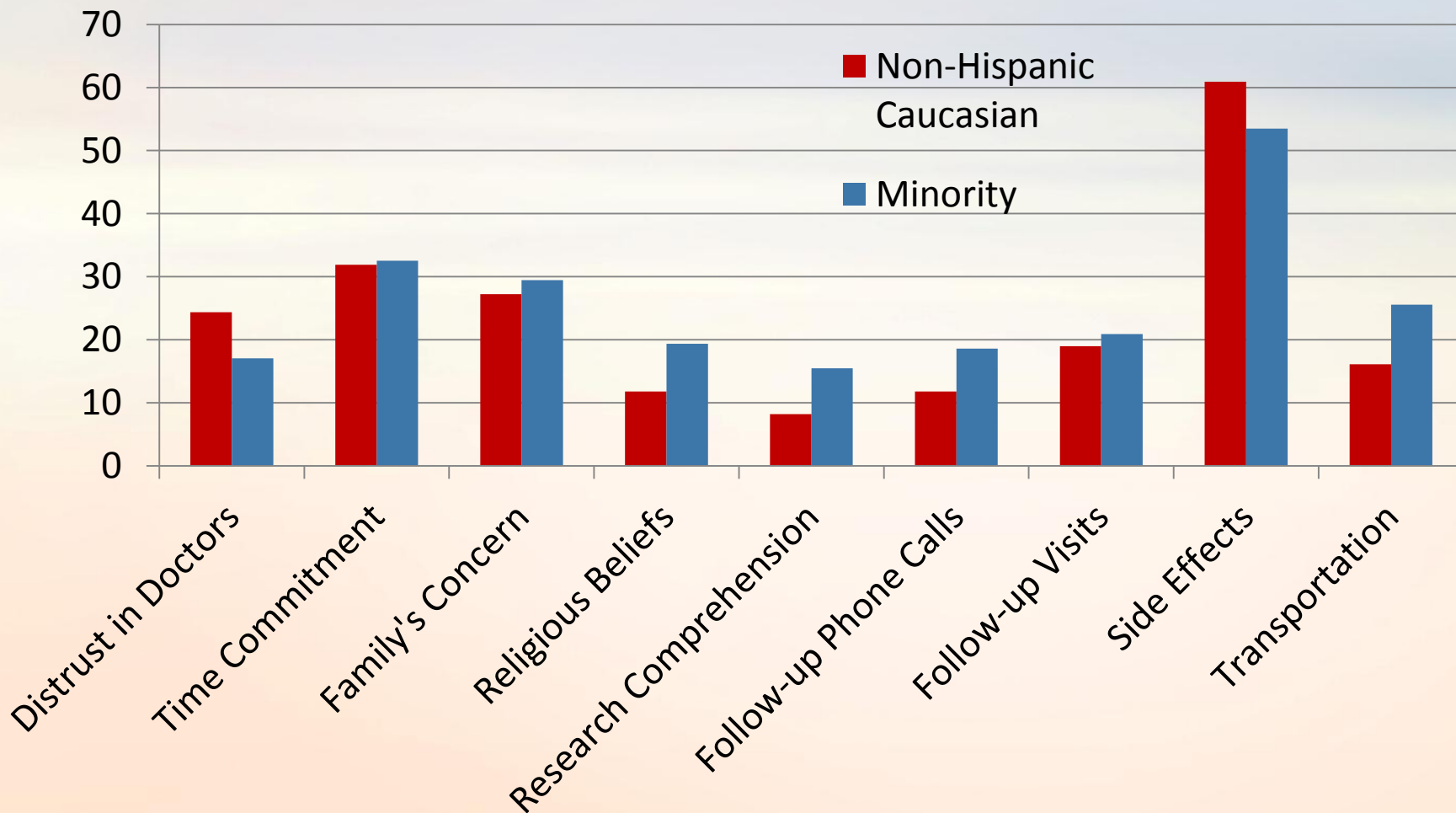


# *Motivators to Research* Participation- Gender

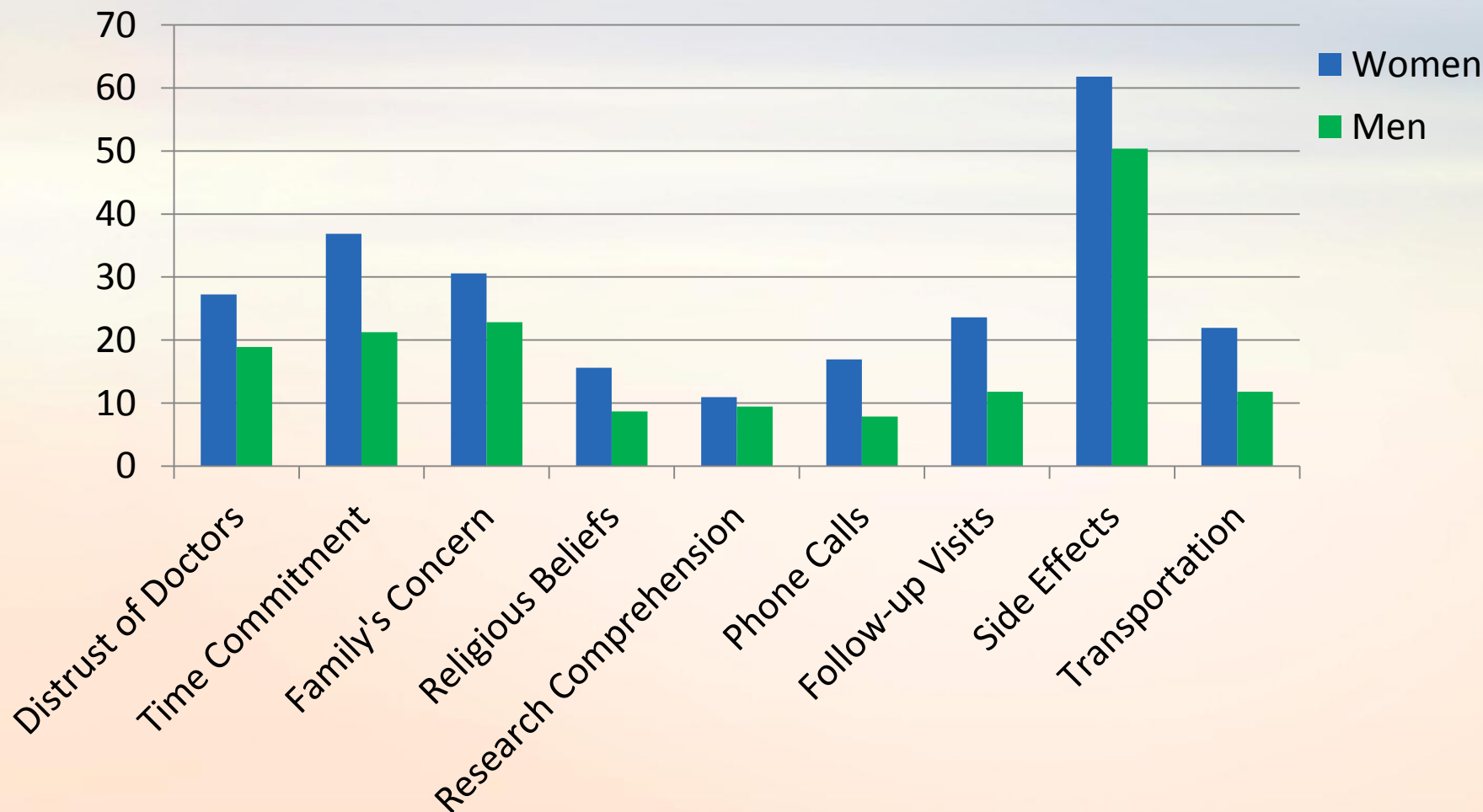




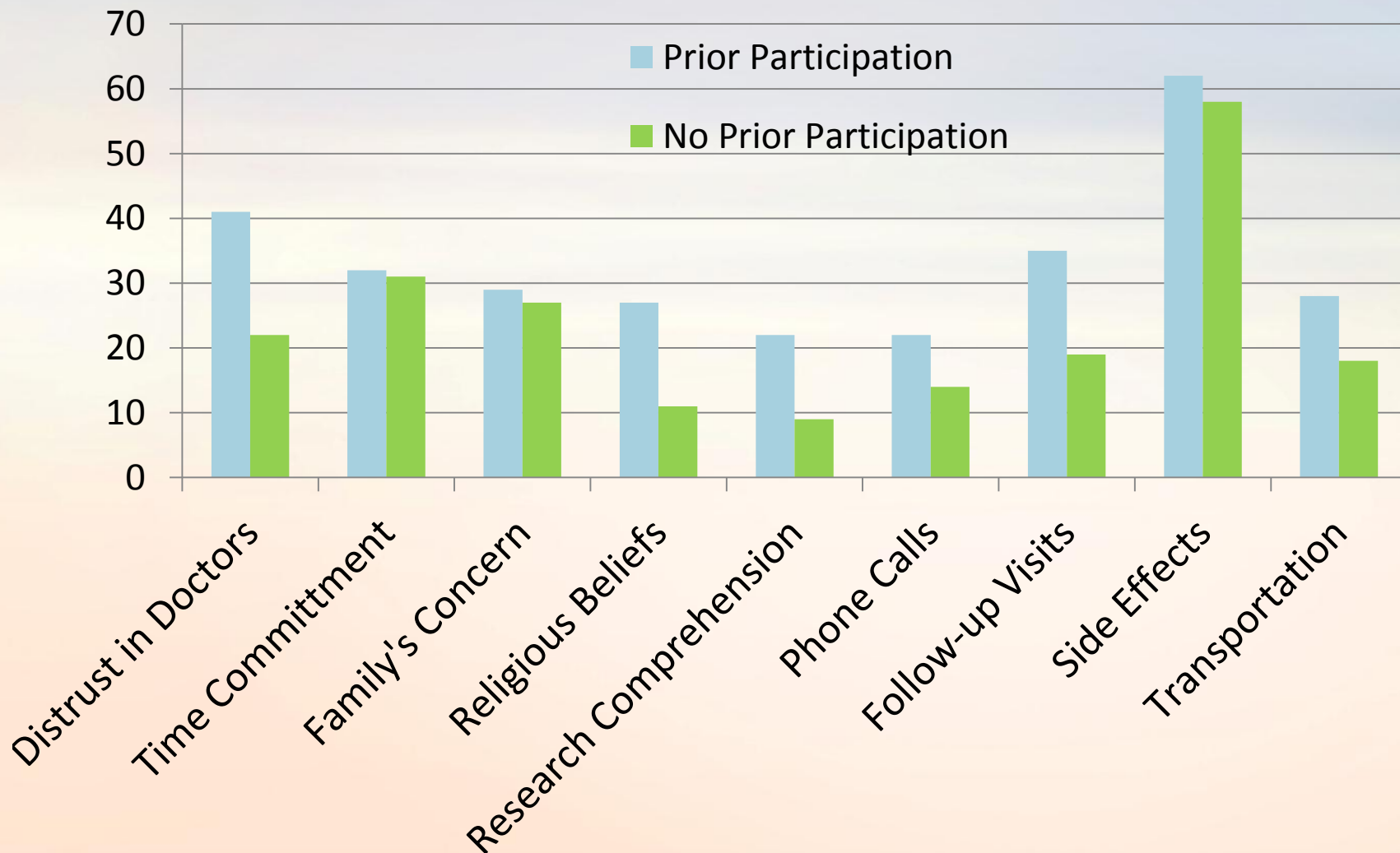
# *Barriers to Research Participation-* Race



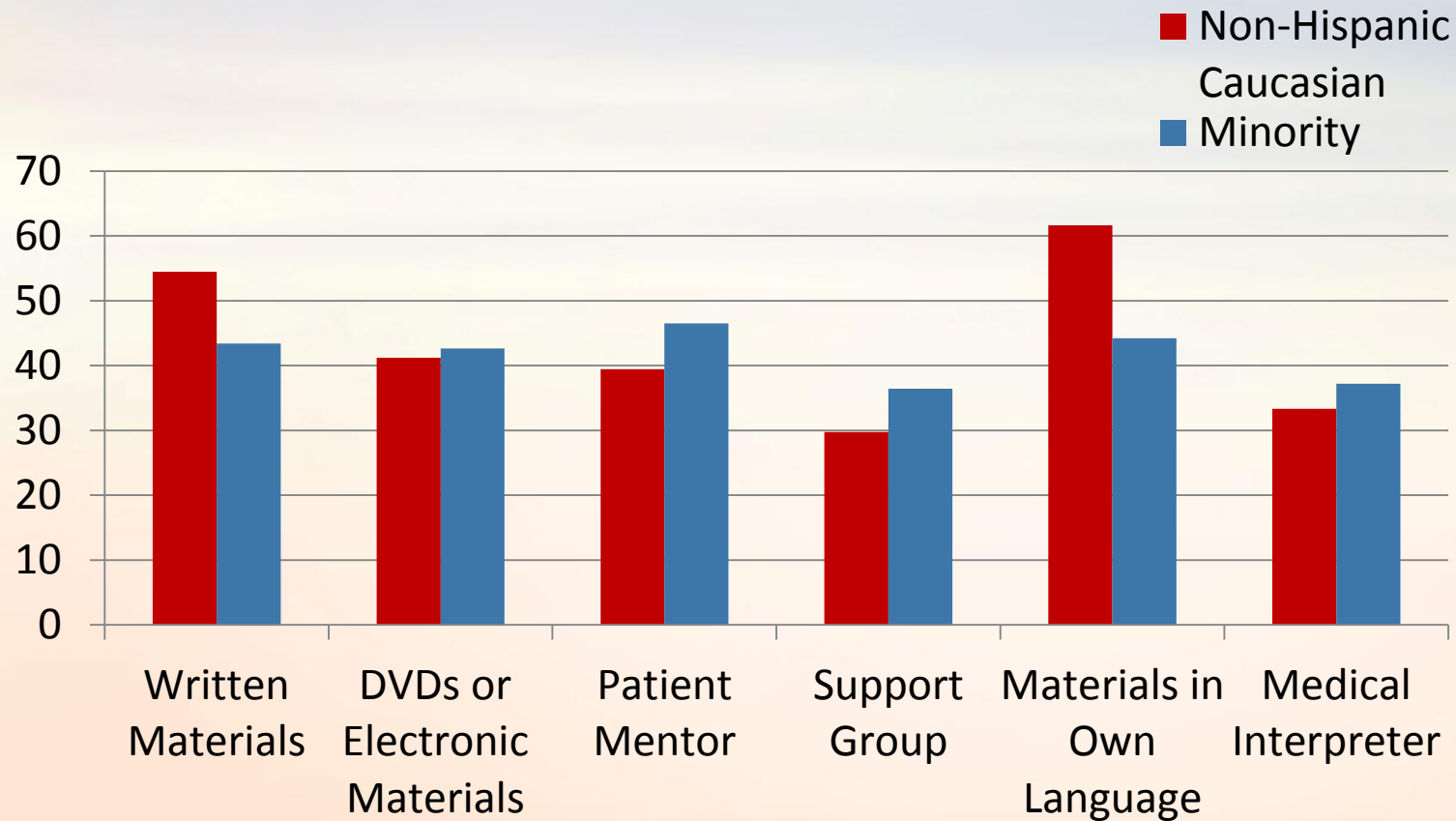
# *Barriers to Research Participation-* Gender



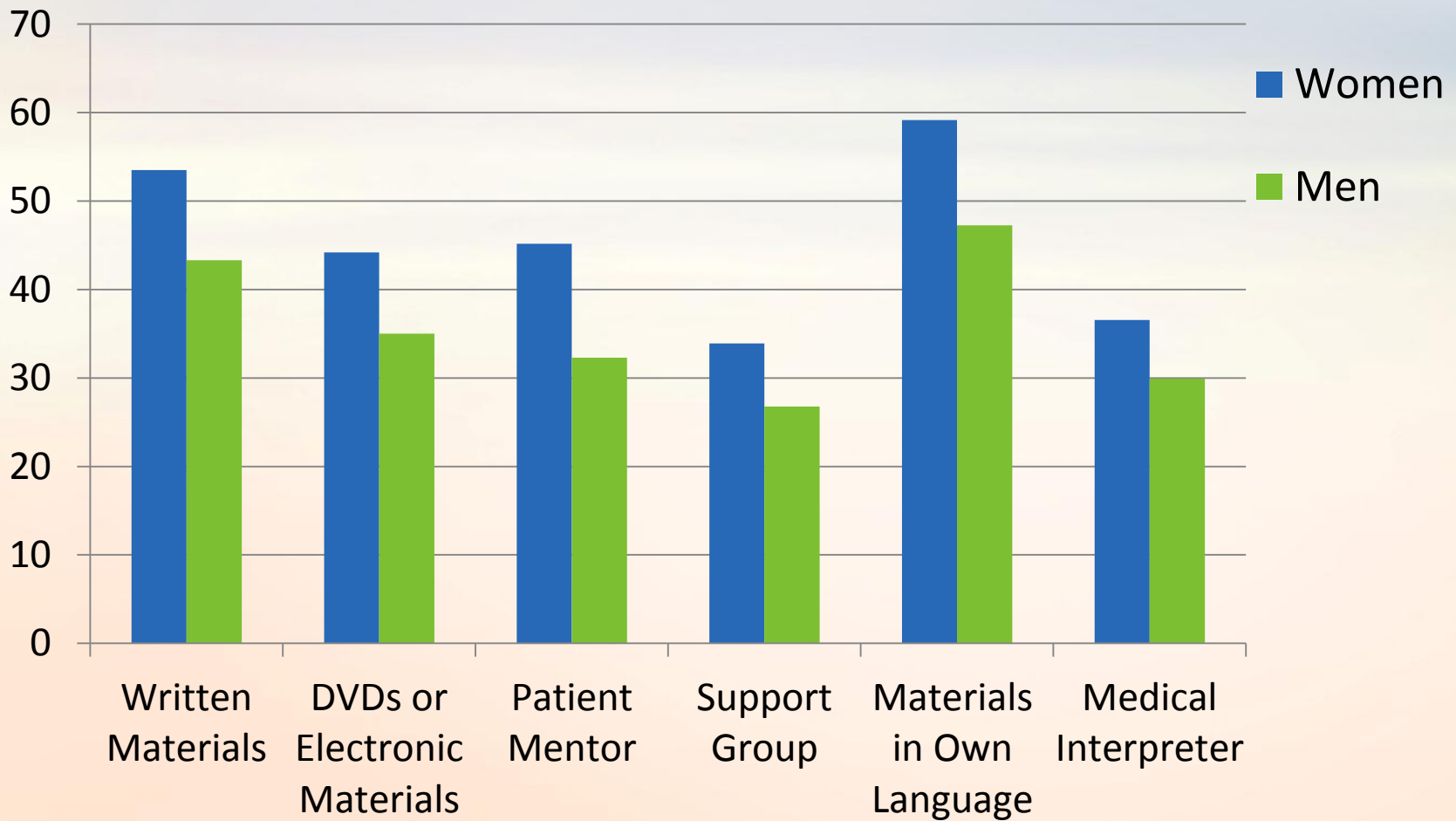
# *Barriers to Research Participation*



# *Resources Aiding in Decision-Making*



# *Resources Aiding in Decision-Making*



# Results

- ❑ **No association between income or education levels and research participation**
- ❑ **Written materials in native language**
- ❑ **Participant mentor or support group resources**
- ❑ **Time and follow-up are barriers**
- ❑ **Financial Incentive is not a motivator in participation.**

# Discussion

- **Know your community**
- **Expand resources to accommodate and encourage participation beyond English-speaking subjects**
- **Foster frequent and thorough communications among physician, patient, family and researcher**

# Share your stories

- Challenges or successes in recruiting diverse populations?
- Participant education, resources and materials?
- Capitalizing on doctor-patient relationship in recruitment and retention?