

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

Anita Kurt PhD, RN
Lehigh Valley Health Network, Anita.Kurt@lvhn.org

Charity Curtis MPH
Lehigh Valley Health Network

Melanie B. Johnson MPA
Lehigh Valley Health Network, melanie_b.johnson@lvhn.org

Henry Liu MD
Lehigh Valley Health Network, Henry.Liu@lvhn.org

Beth Careyva MD
Lehigh Valley Health Network, beth_a.careyva@lvhn.org

See next page for additional authors

Follow this and additional works at: <https://scholarlyworks.lvhn.org/family-medicine>



Part of the [Medical Specialties Commons](#)

Let us know how access to this document benefits you

Published In/Presented At

Kurt, A., Curtis, C., Johnson, M., Lium H., Careyva, B. A., Chang, J., Winter, A., Santiago, C. P., York, W. H., Straubinger, K., Stello, B. (2015, June 29). *Participation in Clinical Research: A Thorough Explanation in Their Own Language Helps Family Medicine Patients Decide*. Presented at the 2015 NAPCRG PBRN conference in Bethesda, MD.

This Presentation is brought to you for free and open access by LVHN Scholarly Works. It has been accepted for inclusion in LVHN Scholarly Works by an authorized administrator. For more information, please contact LibraryServices@lvhn.org.

Authors

Anita Kurt PhD, RN; Charity Curtis MPH; Melanie B. Johnson MPA; Henry Liu MD; Beth Careyva MD; Jerry Chang BS; Alex Winter BS; Claudia P. Santiago BA; Wendy H. York BS, MA; Kathleen Staubinger RN, BSN; and Brian Stello MD

Participation in Clinical Research:

What Influences Primary Care Patients?

Melanie B. Johnson MPA

© 2015 Lehigh Valley Health Network

A PASSION FOR BETTER MEDICINE.™

610-402-CARE LVHN.org

Disclosure of Commercial Relationship(s)

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

- Anita Kurt, PhD, RN
- Charity Curtis, MPH
- Melanie B. Johnson, MPA
- Henry Liu, MD
- Beth A. Careyva, MD
- Jerry Chang
- Alex Winter
- Claudia P. Santiago, BA
- Wendy H. York, BS, MA
- Kathleen Straubinger, RN, BSN
- Brian Stello MD

- This study is grant funded by the Anne and Carl Anderson Trust.

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 ≥ 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

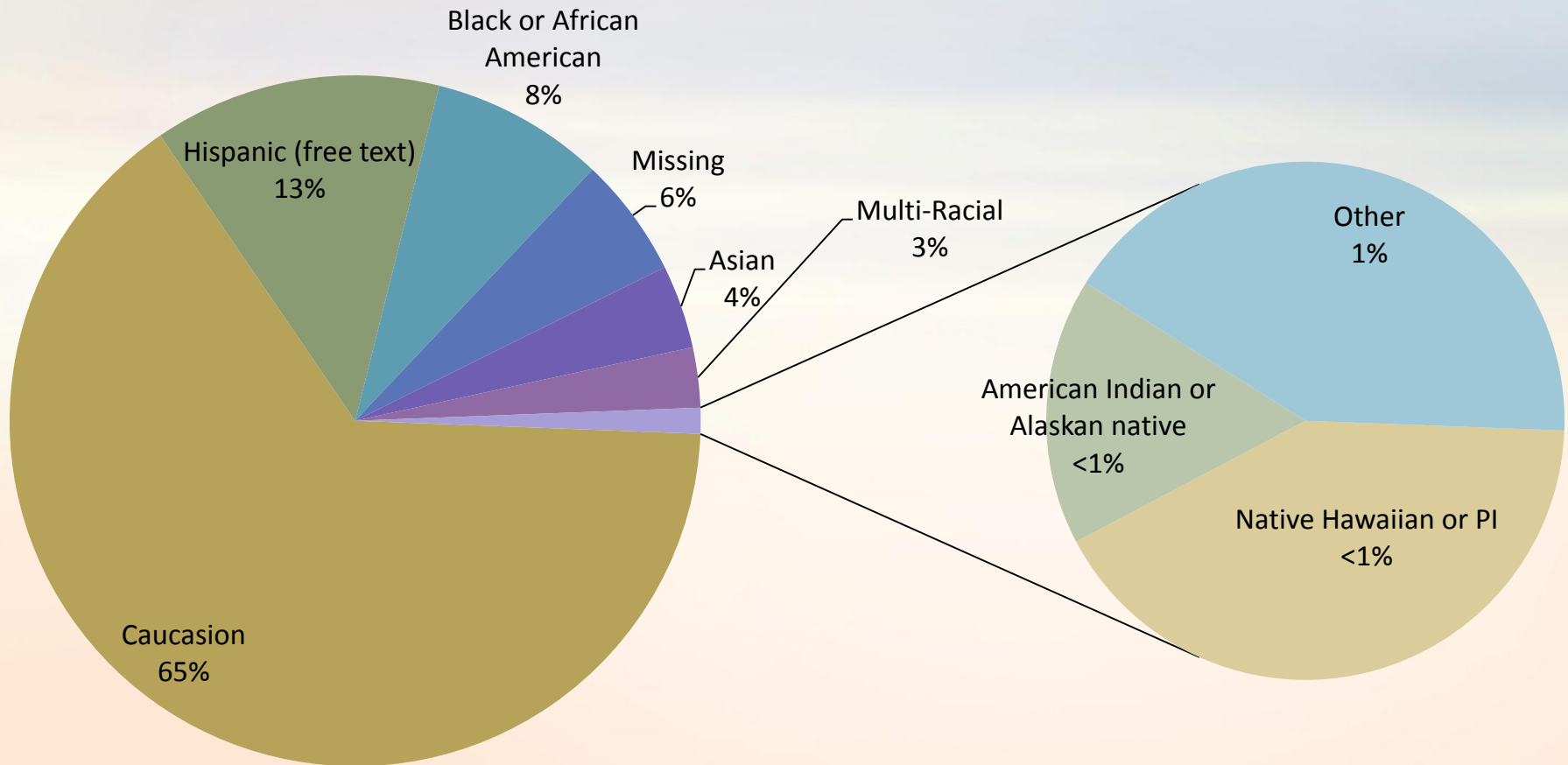
Interim Analysis Method

- **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

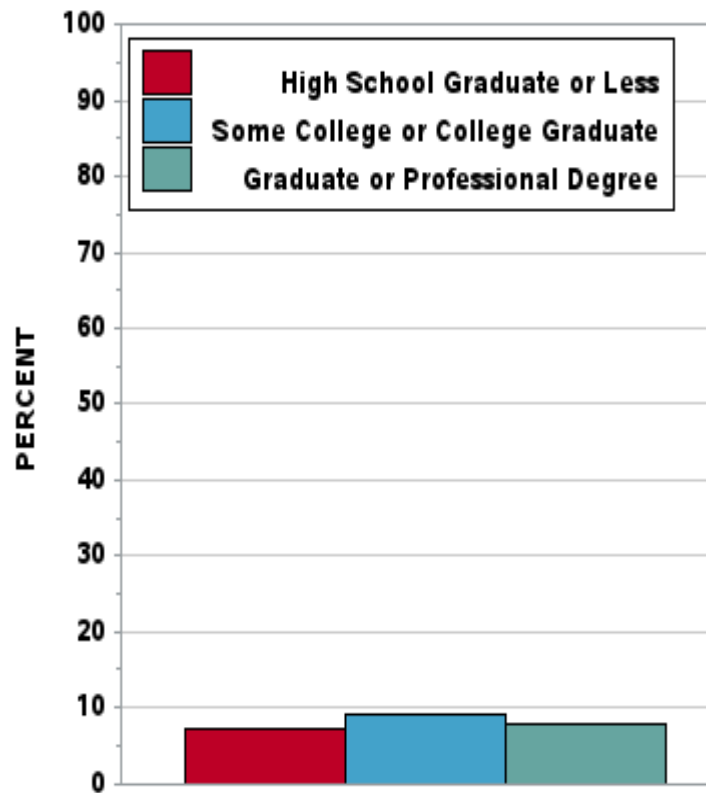
- N= 432
- 70% female
- 91% had not participated in prior clinical research

Participant-Reported Demographics

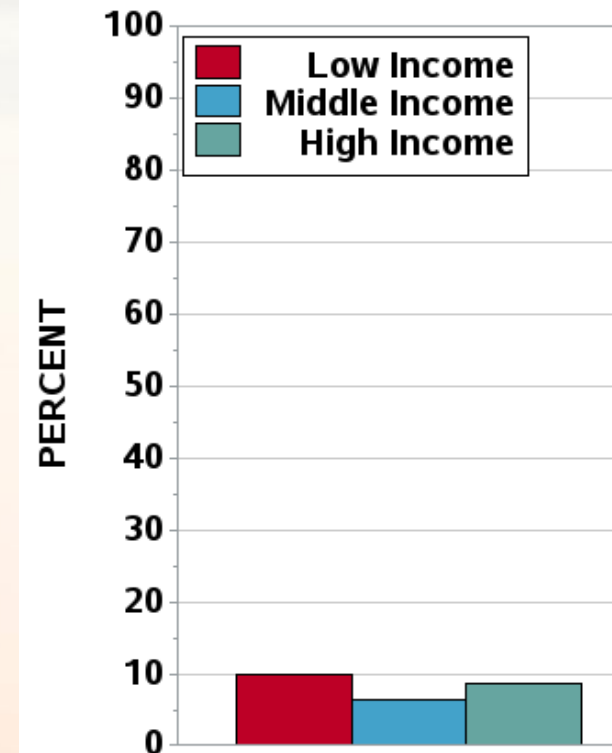


Prior Research Participation

Education Distribution

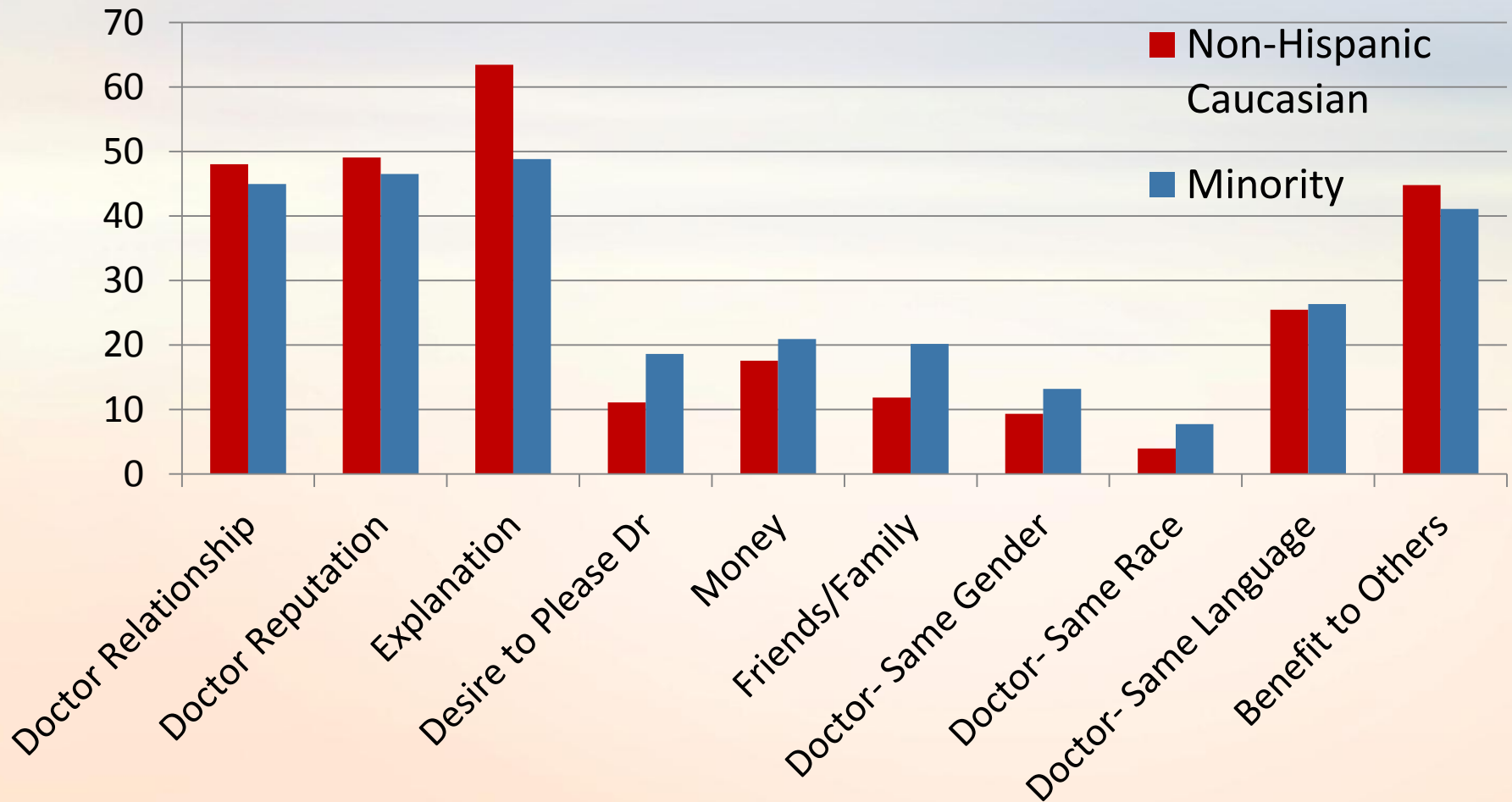


Income Distribution

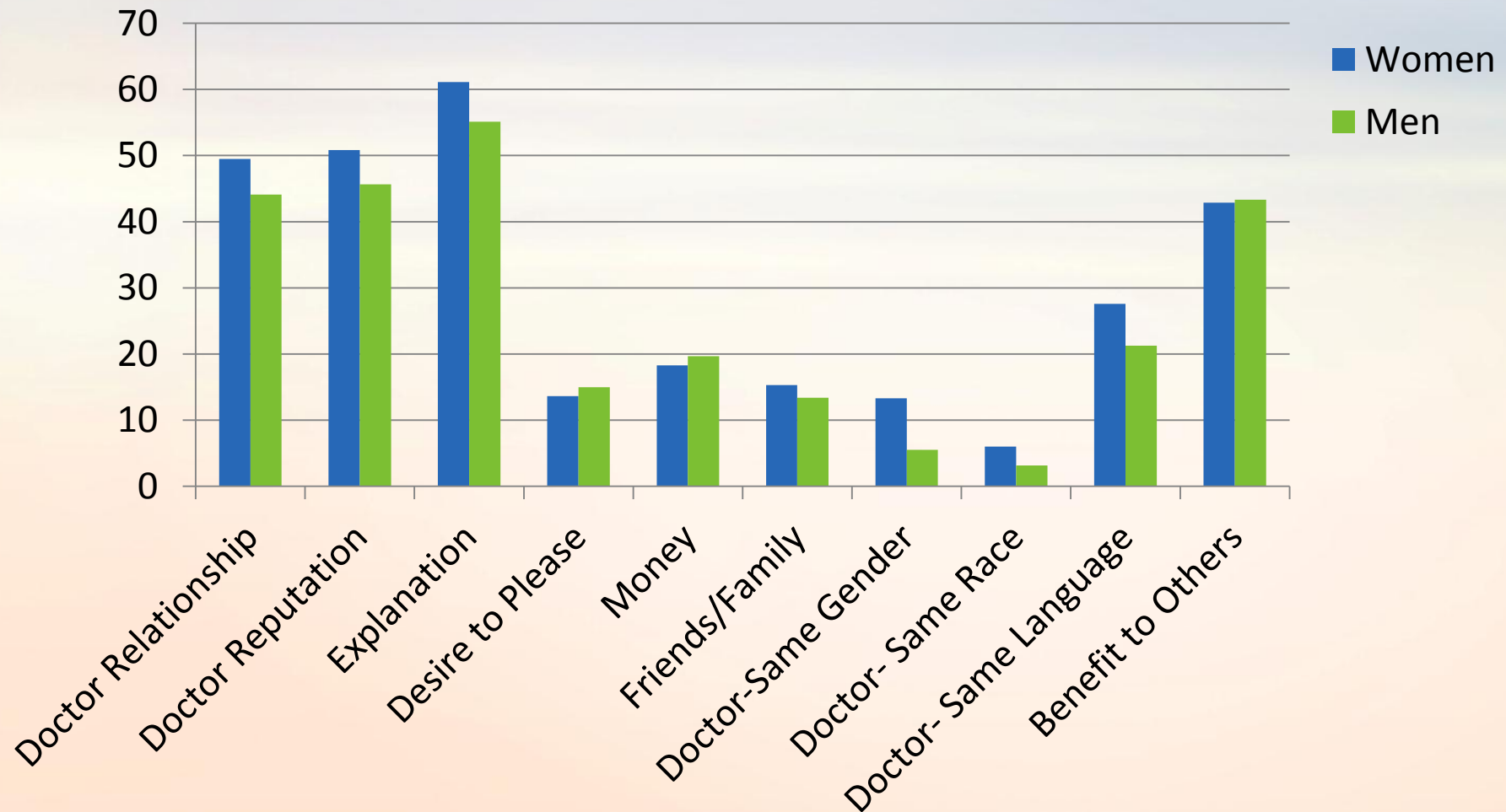


Motivators to Research

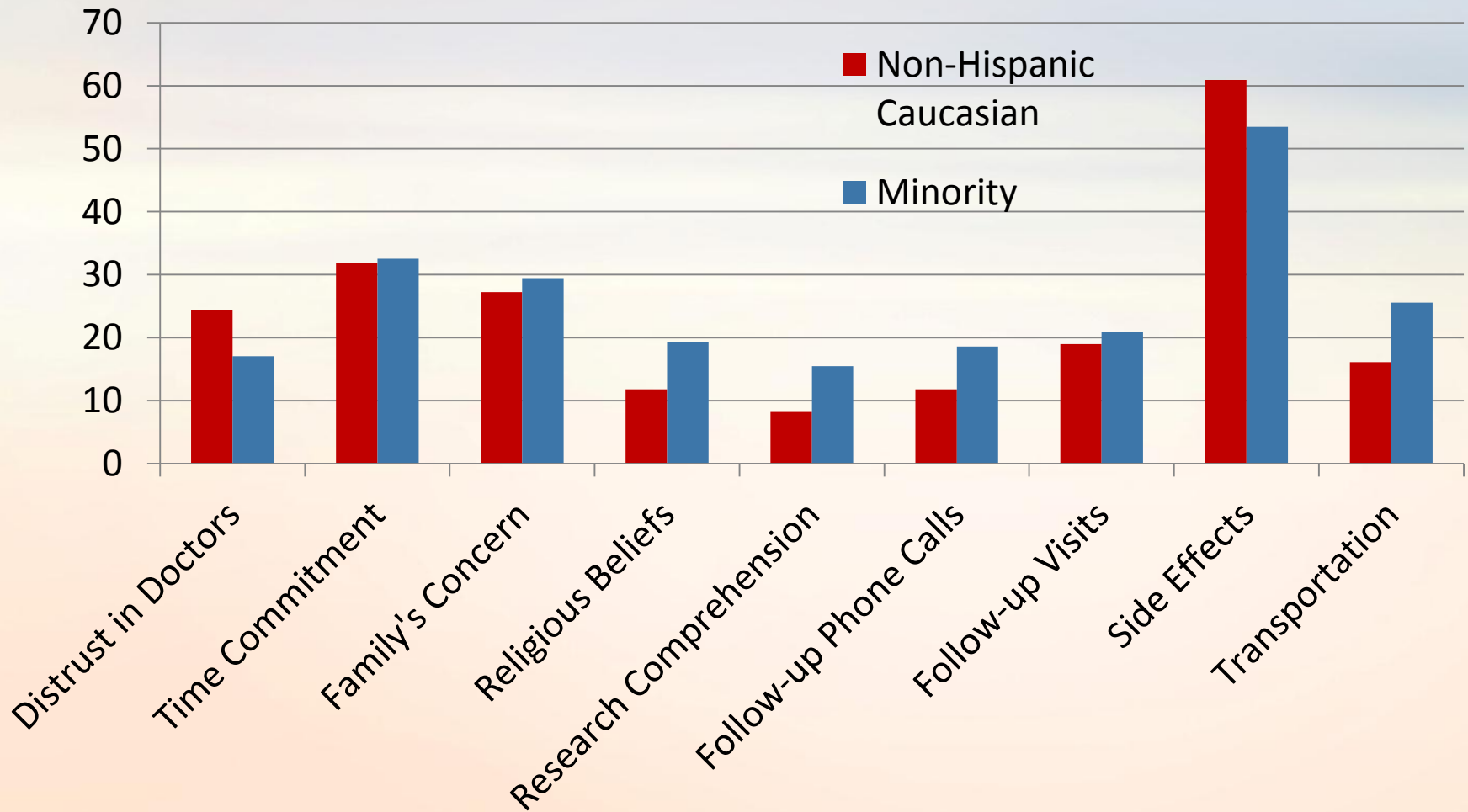
Participation- Race



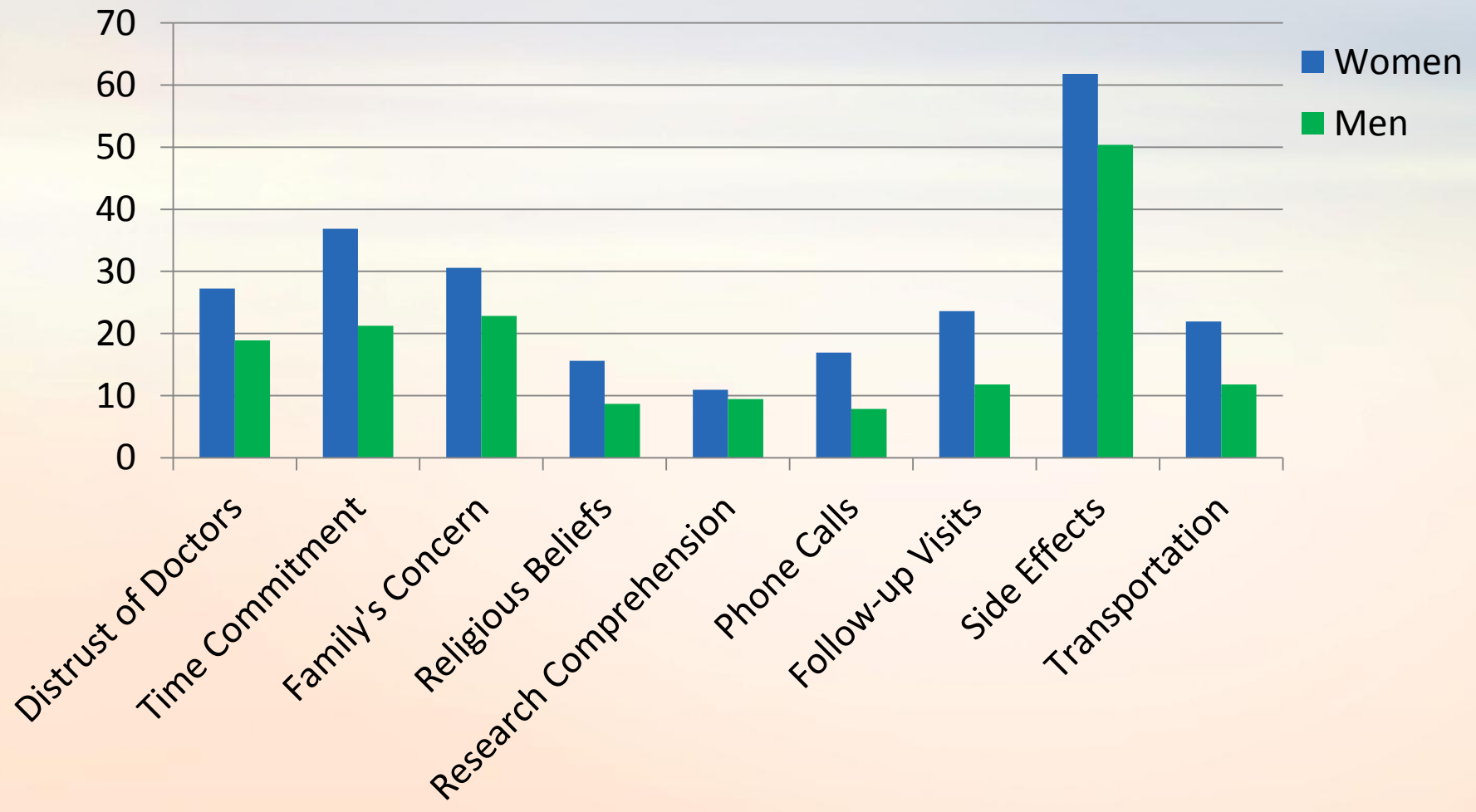
Motivators to Research Participation- Gender



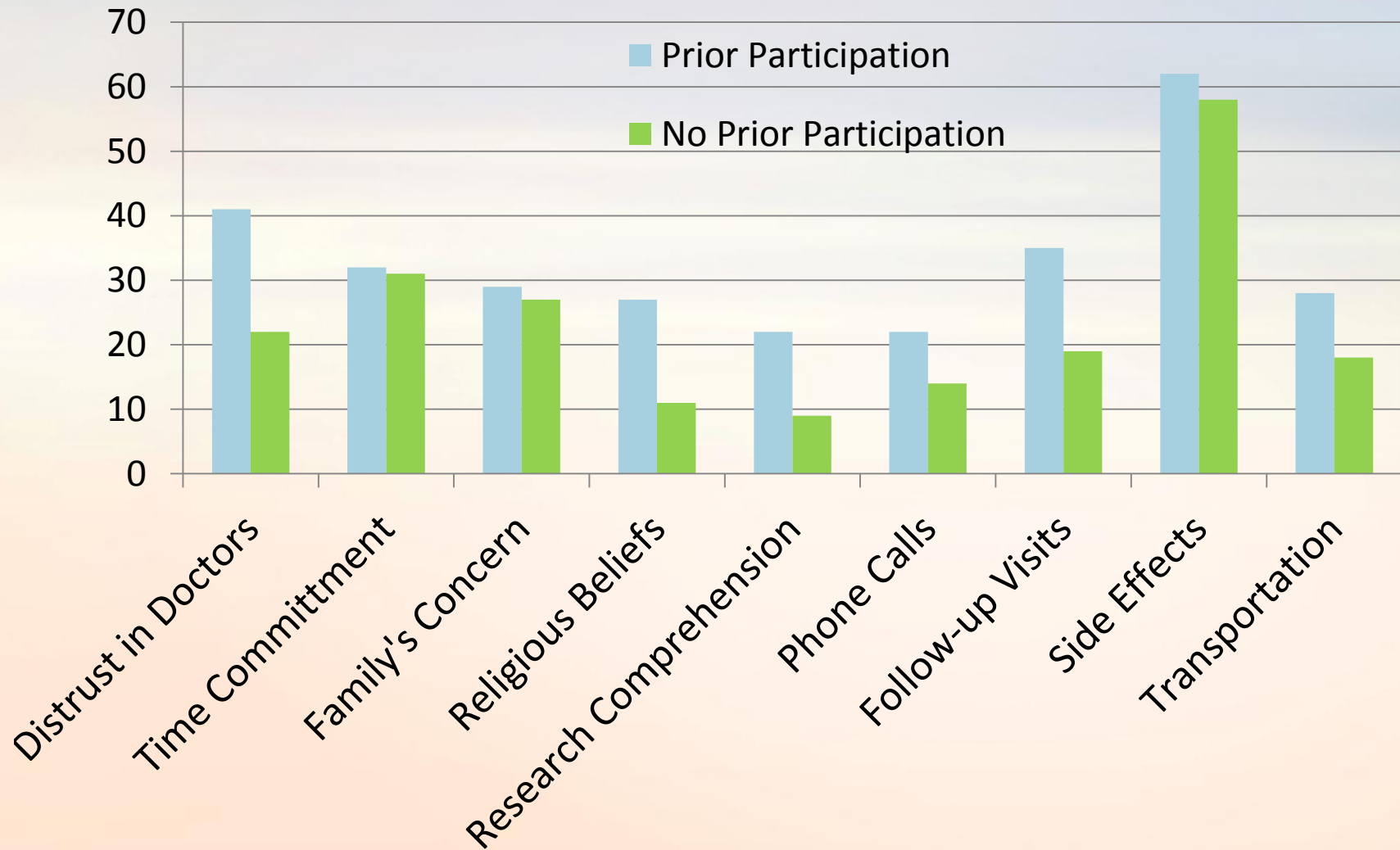
Barriers to Research Participation- Race



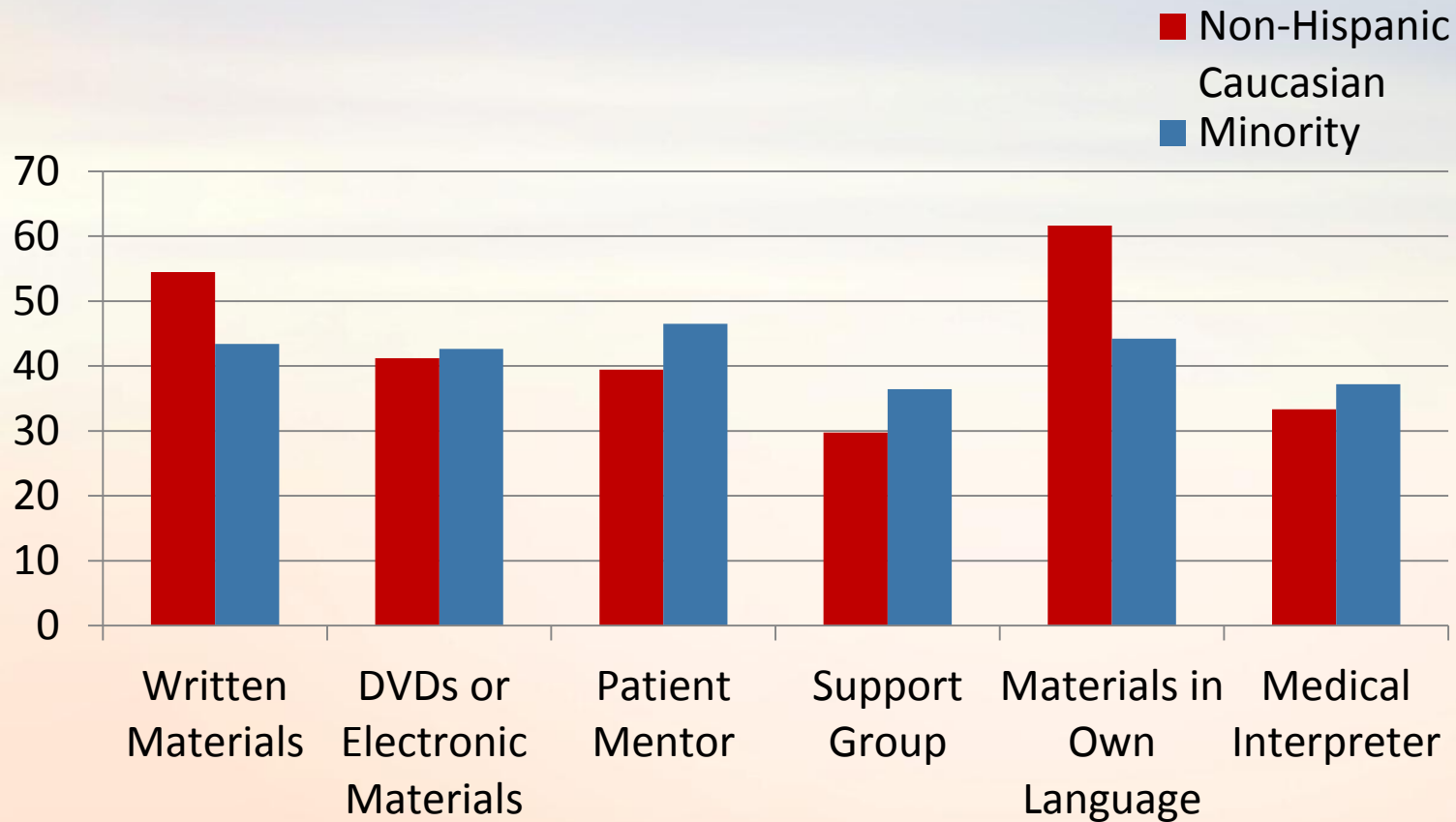
Barriers to Research Participation- Gender



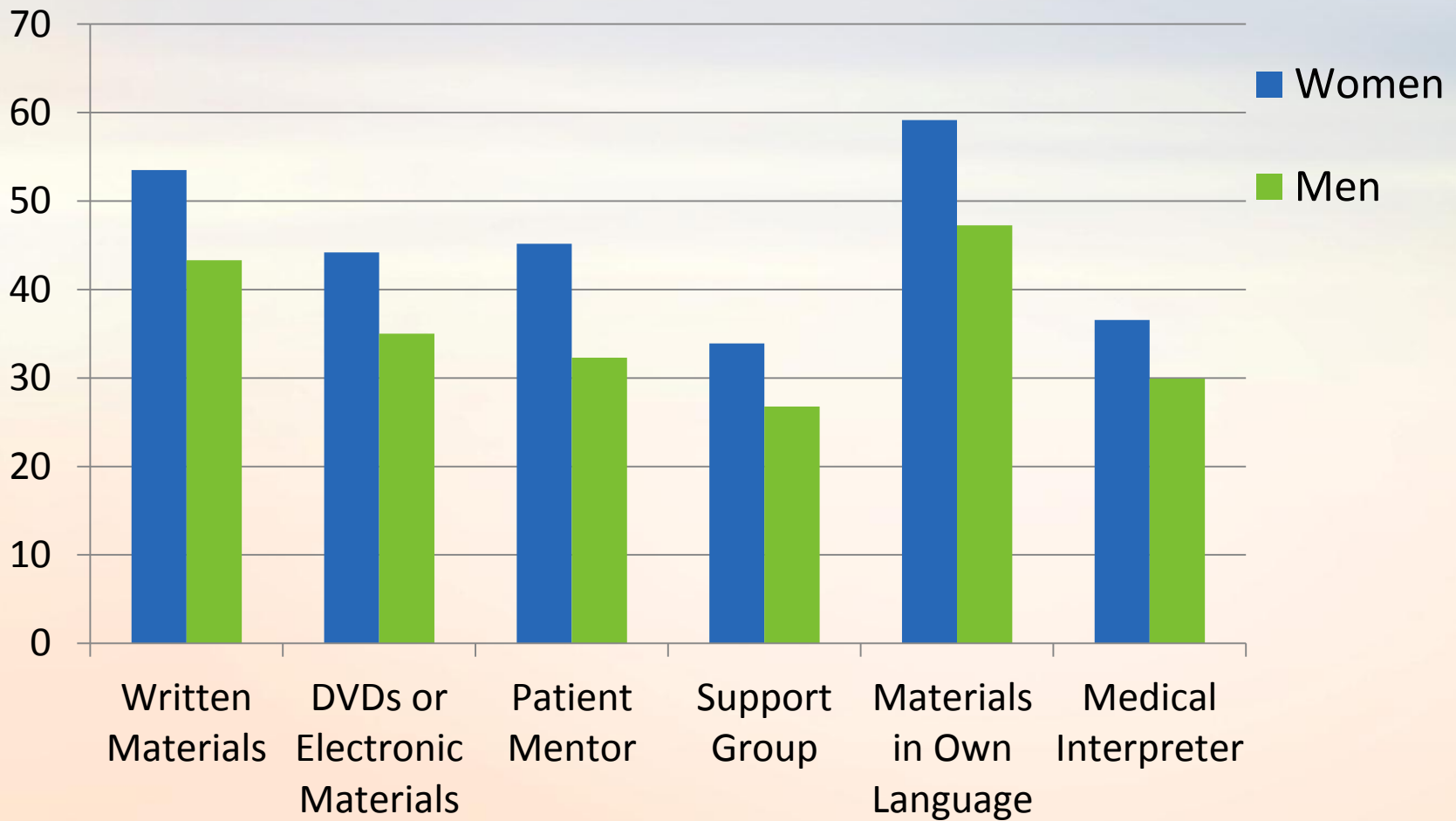
Barriers to Research Participation



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?