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?

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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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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 socio-economic 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

- Caucasian: 65%
- Hispanic (free text): 13%
- Black or African American: 8%
- Missing: 6%
- Asian: 4%
- Multi-Racial: 3%
- American Indian or Alaskan native: <1%
- Native Hawaiian or PI: <1%
- Other: 1%
Prior Research Participation

Education Distribution

Income Distribution
Motivators to Research Participation - Race

- Doctor Relationship
- Doctor Reputation
- Explanation
- Desire to Please Dr
- Money
- Friends/Family
- Doctor-Same Gender
- Doctor-Same Race
- Doctor-Same Language
- Benefit to Others

Red: Non-Hispanic Caucasian
Blue: Minority
Motivators to Research Participation - Gender

- Doctor Relationship
- Doctor Reputation
- Explanation
- Desire to Please
- Money
- Friends/Family
- Doctor-Same Gender
- Doctor-Same Race
- Doctor-Same Language
- Benefit to Others

[Bar chart comparing participation motivation by gender]
Barriers to Research Participation - Race

- Non-Hispanic Caucasian
- Minority

- Distrust in Doctors
- Time Commitment
- Family's Concern
- Religious Beliefs
- Research Comprehension
- Follow-up Phone Calls
- Follow-up Visits
- Side Effects
- Transportation
Barriers to Research Participation - Gender

- Distrust of Doctors
- Time Commitment
- Family’s Concern
- Religious Beliefs
- Research Comprehension
- Phone Calls
- Follow-up Visits
- Side Effects
- Transportation

Women
Men
Barriers to Research Participation
Resources Aiding in Decision-Making

- Written Materials
- DVDs or Electronic Materials
- Patient Mentor
- Support Group
- Materials in Own Language
- Medical Interpreter

Non-Hispanic Caucasian
Minority
Resources Aiding in Decision-Making

Written Materials
DVDs or Electronic Materials
Patient Mentor
Support Group
Materials in Own Language
Medical Interpreter

Women
Men
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?