Disparities in Clinical Research Participation: Motivators, Barriers and Facilitators of Primary Care Patients

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*

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Authors
Anita Kurt PhD, RN; Charity Curtis MPH; Melanie B. Johnson MPA; Henry Liu MD; Beth Careyva MD; Jerry Change BS; Alex Winter BS; Claudia P. Santiago BA; Wendy H. York BS, MA; Kathleen Straubinger RN, BSN; and Brian Stello MD
Background
Enrollment in research is challenging in almost all areas of medicine, and certainly those challenges increase when we attempt to recruit participants that reflect our community’s diverse demographics.

Studies show:
- African American and Hispanic women participate in lesser numbers than Caucasian women.
- Spanish speaking women reportedly participate less than English speaking women.
- As we add race and language as variables, not only do non-Caucasian and non-English speaking women participate in lesser numbers, but also their male counterparts have low representation in research.

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

Participants
- N=432
- 70% female
- 91% had participated in prior clinical research

Results
- No association was found between prior research participation and education levels, nor an association between income distribution and prior participation.
- Patients would be more likely to participate if additional resources were made available, particularly written materials in native language.
- Minority respondents are open to social support resources such as a participant mentor or support group setting.
- 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 new strategies to strengthen the communication loop with physicians, patients and families when providing education on research opportunities and participation.

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