Special Populations Underrepresented in Oncology Research:

Challenges and Solutions to Engage the Hispanic Population

Carlos M. Naranjo, MD. MPH
Special Populations Underrepresented in Oncology Research:

Challenges and Solutions to Engage the Hispanic Population

Carlos M. Naranjo, MD. MPH

Formative Research

Clinical trials representation

Recruitment Challenges

Recruitment Strategies

Conclusion
LATINOS IN THE U.S. ARE

55 MILLION PEOPLE

43% increase over the past ten years.

17% OF THE POPULATION

1 IN EVERY 6 PEOPLE

1 IN EVERY 4 CHILDREN

30% by 2050

Join America's "House of Hope": The Clinical Center at the NIH
Special Populations Underrepresented in Oncology Research:

Challenges and Solutions to Engage the Hispanic Population

Carlos M. Naranjo, MD. MPH

- Clinical trials representation
- Recruitment Strategies
- Formative Research
- Recruitment Challenges
- Conclusion
• Disadvantages in health care access
• Underrepresented as participants in biomedical research
THE PROBLEM

- Lack of understanding of cancer-specific biological factors among Hispanic people.
- Hispanics make up 17% of the population but only 1% of clinical trial participants.
- Fewer than two percent of NCI-sponsored clinical trials focus on any racial/ethnic minority.
- Participation in HIV research studies is overwhelmingly from white males, although Hispanic and black men have higher rates of HIV infection.
Cancer clinical trials, may fail to address unique genetic and environmental factors of Hispanics, that may place them at disadvantages for diagnosis and treatment in the future.

Diagnostic and therapeutic decisions determine that Hispanic patients' well-being and health outcomes are based on data gathered in populations of patients not representative of the Hispanic community who will bear the consequences of these decisions.
Special Populations Underrepresented in Oncology Research:

Challenges and Solutions to Engage the Hispanic Population

Carlos M. Naranjo, MD. MPH

- Clinical trials representation
- Recruitment Strategies
- Formative Research
- Recruitment Challenges
- Conclusion
Challenges

NIH Revitalization Act

Barriers to participation
• In 1993, the NIH instituted policies aimed at increasing the representation of minority populations in clinical trials funded by the agency.

• **The National Institute on Minority Health and Health Disparities.**
  • planning, reviewing, coordinating, and evaluating research activities.

• Sadly, the rate of Hispanic participants enrolled in NIH-funded clinical studies in 2011 was only 8.2% compared to 80% of non-Hispanic participants.
Multiple barriers

In 1956, the pill’s clinical trials began in Rio Piedras (San Juan, PR). A fifth of the women involved in the test suffered side effects. None of the women were told that they were taking part in an experiment. The side effects were largely brushed aside by the pill’s developers.

Lack of trust

- Accessibility
- English proficiency
- Stigma
- Time constrains
- Transportation
- Loss of wages
- Cultural taboos / myths
Special Populations Underrepresented in Oncology Research:

Challenges and Solutions to Engage the Hispanic Population

Carlos M. Naranjo, MD. MPH

- Clinical trials representation
- Recruitment Challenges
- Recruitment Strategies
- Formative Research
- Conclusion
Contextual Factors
Contextual Factors

- Faith vs scientific data
- Family – part of medical decision
Interventions

- Educational material (in Spanish and English)
- Create and record social media commercials
- **Training sessions among health care providers**

Accrual Quality Improvement Program (AQuIP) Toolkit
Special Populations Underrepresented in Oncology Research:

Challenges and Solutions to Engage the Hispanic Population

Carlos M. Naranjo, MD. MPH

- Clinical trials representation
- Recruitment Strategies
- Formative Research
- Recruitment Challenges
- Conclusion
Importance of advocacy for diversity and inclusiveness in oncology clinical trials

There is an urgent need for more oncology research focusing on Hispanics in the U.S.

Hispanic population's strong willingness to participate in biomedical research
  Benevolence
  Prevention, diagnosis, and treatment

Researchers needs to be knowledgeable and display tact and cultural sensitivity.
Thank you