Why Enhancing Diversity in Clinical Trials is Good Policy

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The “Underrepresented” in Clinical Trials

- Underserved
- Racial/Ethnic
- Women
- Special Health Needs, i.e.; disabled, chronic illness, etc.
- Uninsured
- Children – Adolescents
- Rural
- Immigrants
- Elderly
- Low Income

EDICT
Eliminating Disparities in Clinical Trials
Two Main Barriers to Cancer Healthcare & Clinical Trials

- INFORMATION
- COMMUNICATION
Understand Cultural Transformation: BUILD a Relationship with the Community

- Know the demographics
- Understand major issues affecting the community, (i.e. cancer, obesity, mistrust, etc.)
- Search for trusted collaborators/partners within the Community
Results of EDICT Focus Groups

Issues related to Disparities

Community Perspective

- Mistrust
- Lack of awareness
- Cultural barriers
- Language/Linguistics differences
- Low literacy
- Socio-economic obstacles
- Cost/Lack of insurance
- Study design eligibility criteria

* WE NEED POLICY TO ADDRESS THESE ISSUES!
Understanding the Mistrust

• Perception vs. Reality

• History of Medical Abuse
Results: MAMMAS© Survey

- 83% were aware of some form of medical abuse that occurred.
- 89% believed mistrust contributes to the lack of participation into clinical trials.
- 71% felt that patients may have been deceived or misled by healthcare organizations.
- 74% believed that healthcare organization have experimented on patients without their knowledge.
- 78% felt that patient information is not always kept private.
- 80% were cautious about healthcare organizations.
- 87% stated that mistakes are usually covered up by healthcare organizations.
- 86% were conscious of the importance of cancer screening, but felt that fear may be hindering many from access to care.
Who is a Promotor (α)- Community Health Worker?

A person who, with or without compensation:

- Represents the ethnic, socio/economic and educational traits of the population he/she serves;

- Trained to bridge the gap that exists between communities and health and human service systems;

- Respected and trusted by their neighbors and peers who provide informal counseling and social support;
Promotores + Community Health Workers as Clinical Trial Navigators
# Promotor (a) /CHW Curriculum

## Teaching Skills
- Plan + Effect Presentation
- Teach on “How to talk” to your doctor

## Communication Skills
Talking with someone who:
- has a sexually transmitted disease,
- may need mental health services

## Service Coordination Skills
- CHIP/ CHIP Perinatal
- Understanding the role of community health centers

## Interpersonal Skills
- Health Literacy
- Cultural Competence

## Advocacy Skills
- How to advocate about health issues for Latinos or other minority groups
- How to advocate for children

## Capacity-Building Skills
- Teaching skills for behavior change
- How to motivate your patient & their family about follow up

## Organizational Skills
- How to prepare for a DML Health Fiesta
- How to prepare and analyze Pre and Post Surveys

## Knowledge Base on Specific Health Issues
- Breast Cancer
- Cervical Cancer and the Human Papillomavirus (HPV)
- Cardiovascular
- Perinatal
- Disaster Preparedness
- Diabetes
Evidence-Based Intervention

- The Promotoras model is adaptable as evidenced by its use in addressing a number of community issues, including HIV/AIDS, Diabetes and other chronic illnesses, and community organizing. While their roles, job titles, responsibilities and activities may vary depending on client or community needs, they save lives.
Policy Recommendations

- **Community Input** - in the **design** of the protocol to ensure cultural proficiency of investigators.
- **Community Outreach** - build relationship with local CBOs/FBOs to establish trust.
- **Community Participation** - Support and building community capacity to support trials, as well as funding to **compensate** community groups for their contributions.
- **Community Participatory Research** – not just on paper. Engage Promotores/CHW as Clinical Trial Navigators.
“If you want to move people—it has to be towards a vision that’s positive for them; that taps important values, that gets them something they deserve AND It has to be presented in a compelling way that they feel inspired to follow”

Dr. Martin Luther King, Jr.