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Center for Clinical and Translational Science

# Strategies for Minority Recruitment

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February 18 , 2016



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# Importance of Minority Participation in Clinical Research

## Rationale

- Increased diversity in clinical trials could help research find better ways to fight diseases that disproportionately impact certain populations, and may be important for the safe and effective use of new therapies. Ex. AA men are twice as likely to die from prostate cancer than Caucasians, but represent only 4% of prostate cancer clinical trial participants.



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# Barriers to Recruiting Minorities for Clinical Trials

- Recruitment issues
  - Minorities unaware of medical research ( or are not ever being asked to participate?)
  - Lack of cultural sensitivity in communications
  - Lack of resources to treat the uninsured if found to be sick
- Potential Participants concerns
  - Lack of awareness of benefits to participation
  - Sense that participants only give and get nothing
  - Concerns about signing the ICF
  - Fear of being a guinea
  - Fear of the unknown

Source: Examination for Community members' Researchers' & Health Professional perceptions of barriers to minority recruitment (Robinson JM, 2007)



# Barriers to Recruiting Minorities for Clinical Trials

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- **Psychosocial/socioeconomic issues**
  - More pressing survival problems
  - Cultural beliefs/religious beliefs
  - Mental illness, homeless
- **Historical experience with main health care system and clinical research (i.e. mistrust of medical community).**
  - Previous negative experience (The Tuskegee experiment 1932-1972; Gutamalan Project 1946-1948; Puerto Rico Pill Study 1954-1964)
  - Literacy issues
  - Mistrust due to discriminatory social/historical/legal experiences
- **Resources/Financial considerations**
  - Lack of health coverage to reimburse medical interventions in protocols
  - Presentation at late stage for many minority patients
  - Dismal past record of translating research into practice in underserved community.

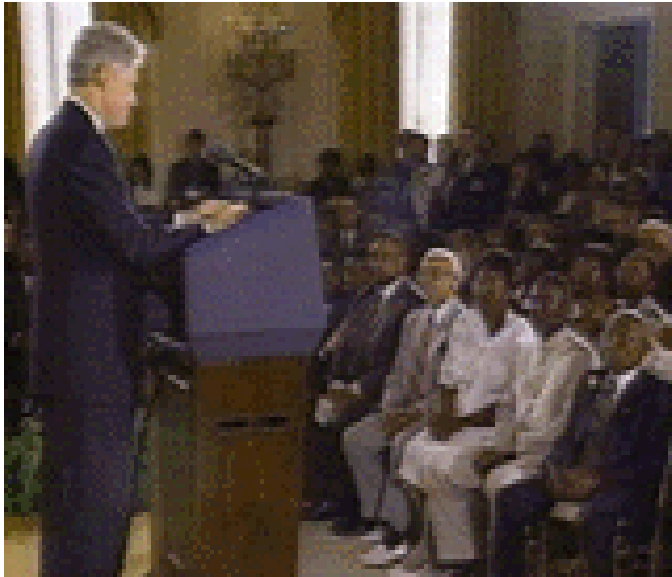


# US Government's Apology

## PRESIDENT CLINTON:

The United States Government did something that was wrong, deeply, profoundly, morally wrong. It was an outrage to our commitment to integrity and equality for all our citizens. We can end the silence. We can stop turning our heads away. We can look at you in the eye and finally say on behalf of the American people what the United States Government did was shameful, and I am sorry.

**May 16, 1997**





# U.S. Apologizes to STD Experiences in Guatemala

- Hillary Clinton (October, 2010) and Health and Human Services Secretary Kathleen Sebelius offered extensive apologies for actions taken by the U.S. Public Health Service. "The sexually transmitted disease inoculation study conducted from 1946-1948 in Guatemala was clearly unethical," according to the joint statement from Clinton and Sebelius. "Although these events occurred more than 64 years ago, we are outraged that such reprehensible research could have occurred under the guise of public health. We deeply regret that it happened, and we apologize to all the individuals who were affected by such abhorrent research practices." Hillary Clinton and the President Barack Obama called the Guatemalan president Alvaro Cabellaros to reaffirm the importance of the U.S. relationship with the Latin American country



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# Barriers to Recruiting Minorities for Clinical Trials

- **Influence of Researchers (as potential barriers) to low participation rate**
  - Attitudes of Researchers toward engagement with minority communities.
  - Historical, approach of researchers (not one of partnership).



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# Barriers to Recruiting Minorities for Clinical Trials

- Not linking research to what the minority communities need
- Lack of minorities PIs ( or too few?)
- Lack of bilingual researchers
- Inappropriate outreach methods (i.e., recruitment & retention strategies)





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# Strategies to Engage Minority communities

- Positive practices for researchers to engage the target community: Define your Target Community
- Understand the socio-cultural and historical factors associated with mistrust of research
  - Diverse research teams, and
  - Match race of recruiter (is perceived as being effective)
  - Knowing the “right” amount of information ; and
  - How to deliver that information
  - Use of partnering with community organizations (e.g., faith based organizations; organizations that provide social services); Use of community Advisory Boards



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# Strategies to Engage Minority communities

- Sources of Information About Community
  - Hospital Public Affairs
  - Hospital Social workers /out reach coordinators/case mangers; Hospital Patient Advocates, hospital Chaplains,
  - Use of physician referrals?
  - Use of Research registries?
- Community Resources for Support
- Faith-based & social services organizations, local chapters of ethnic medical societies, National Medical Association; Hispanic Medical Association, National Black Nurses, Association of Black Aging?, etc



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# Strategies to Engage Minority communities

- Sustain Relationship with the Community Partners
- Building Trust with the target population community (i.e., identify with community)
- Develop ongoing communication (i.e., “listening “ thus get the issues to be discussed
- Use collaborative approach (e.g., ask for help)
- Help them leverage on-line tools
- Provide public acknowledgement of support- newsletter, letter of thanks from high-ranking administrator or investigator; recommendations
- Create webinars/other virtual learning that showcase your partners (Google hangouts, Twitter chats)



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# Strategies to Engage Minority communities

- Leveraging Ethnic Media: (Radio, print, Online)
  - Contact national ethnic media associations, but also work with your local media
  - Buy across all platforms (traditional and online)
  - (e.g., the inquirer, impre Media, Baltimore times, Kiss 104.1, HU Radio, Radio One, Beacon Newsletter, etc)



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# Strategies to Engage Minority communities

- Leveraging, and Building , cost-free Media
  - Public service announcements
  - Community calendars
  - Radio and print community outreach coordinators
  - Flyer distribution at community venues,
  - Work with local journalists ( e.g., national Association of Black Journalists)



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# Major Key Points

- Develop a profile of your community and target participants in order to determine culturally appropriated recruitment and retention strategies
- Solicit the support of community gatekeepers and community-based organizations to build trust and optimize recruitment and retention results
- Use free, local media outlets to extend reach
- Leverage value-added components of paid media to extend investment
- Sustain the involvement of community partners to enhance retention
- Provide culturally appropriated information to diverse trial participants to increase retention potential.



# Other Important Information

A detailed course on these topics and more can be accessed at:

[www.sitelms.org](http://www.sitelms.org)

by searching on the course number:Od-017234

A similar course, “ **Ethics, Regulations & Study Implementation involving Human Subjects**” will be held on Feb 26 (8:30-4:00PM) at NRH (off Irving st. NW, DC). Co-sponsored by GHUCCTS.

Recently published article: Otado et al., (Oct., 2015), “culturally competent strategies for recruitment and retention of African American populations into clinical trials”. Link below for full article.

<http://onlinelibrary.wiley.com/doi/10.1111/cts.12285/epdf>