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# **The Recruitment of Racial and Ethnic Minority Older Adults for Clinical Research:**

## **Best Practices, Tips, and Lessons Learned**

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# A little Bit About Me.....



- Education
- Professional Experience
- Research
  - K23
  - NIA R01
  - PCORI Health Disparities Large Research Award
- Social Justice

# Agenda

- Discuss some of the common barriers to recruitment of racial and ethnic minority older adults for clinical research.
- Identify empirically supported strategies for enhancing recruitment of ethnic minorities in clinical research.
- Tips and lessons learned from my own research.
- Q & A

# The Issue.....

- People of color constitute a significant and rapidly growing portion of the older adult population in the U.S.
  - In 2010, people of color made up 20 percent of the nation's total 65+ demographic, a figure that will more than double by 2050.
- Older adults of color face significant disparities in health and health care access, economic security, housing, employment, community support, and much more.
  - Including access to and engagement in research.

# The Issue Cont.

- Unfortunately, racial and ethnic minorities in general experience more preventable diseases and poorer health outcomes (i.e. health disparities)...however they are not included in research studies as often as non-Hispanic Whites.
- Even though researchers who get NIH funding have been required since 1993 to report race, ethnicity, and gender of participants in their research proposals, this disparity remains.

# The Issue Cont.

- *"The inclusion of minorities affects more than minority health and health disparities. It is also a question of social justice—and of good science. To be truly thorough and meaningful, our clinical studies must include diverse populations".*
  - Eliseo J. Pérez-Stable, M.D.  
Director, National Institute on Minority Health and Health Disparities
- Research is needed to better understand and address a variety of issues related to health and aging and to ensure novel interventions are relevant for this population.
- Even though clinical research for older minority adults is recognized as a priority, conducting this kind of research is complicated.

# Recruiting for Clinical Trials

- According to NIMHD, racial/ethnic minorities account for fewer than 10% of patients enrolled in clinical trials .
  - Historically low participation rates
  - Contributes to the failure and early termination of clinical trials.
- Not just an issue for older racial/ethnic minorities.
  - Only 4 in 10 Americans have a positive impression of clinical trials and only about one-third of Americans would be likely to enroll in one.



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# Barriers to Recruitment of Older Racial/Ethnic Minorities

# Barriers to Recruitment

## -Patient Level

- Distrust
  - Of physicians, researchers and research generally
- Negative beliefs about clinical trials
  - Fear of harm
- Low health literacy/education
- Language discordance
- Family Composition
- Stigma

# Barriers to Recruitment

## -Study Level

- Unmet transportation needs
- Competing obligations, time, cost
- Language discordance
- Lack of culturally sensitive materials/marketing plans
- Use of invasive procedures

# Barriers to Recruitment- Study Team

- Lack of training
  - Communication skills/interpersonal process
  - Informed consent documents
  - cultural humility/empathy/bias
- Lack of diversity among study teams
- Lack of key community stakeholder engagement



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# Best Practices for Recruitment

- 1) Professional Referrals
- 2) Social Marketing

# Professional Referrals

- Referrals directly from **trusted professionals** can be a valuable recruitment strategy for racial and ethnic minority elders.
  - Especially when used as part of a broader, community centered approach.
- Ethnic minority elders may view healthcare professionals (especially those who are culturally accepted and speak the same language) as being more legitimate and knowledgeable than nonprofessional referral sources.
- Requires building trust and relationships with trusted medical professionals in hospitals and community settings.

# Social Marketing

- Effective because it connotes a sense of professional legitimacy when presented in a way that facilitates involvement of ethnic minority elders.
- Providing **targeted, culturally relevant materials** containing considerable information about the projects (e.g. eligibility requirements, detailed bilingual descriptions, noting the availability of bicultural, bilingual staff etc.).
- A dedicated website or “800” number in all media provides a toll-free way to contact the research team and enhances legitimacy.
- Similar marketing on social media....yes older adults are on social media 😊
- Adds that run on TV, the radio, and flyers and brochures located in areas frequently visited by older people of color.



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# Strategies to Enhance Recruitment & Retention

## Tips and Lessons Learned

# Building Trust

- Identify key informants from community-based organizations serving ethnic minority families , caregivers etc.
  - These healthcare providers (typically physicians, nurses, social workers, in home support service staff, etc.) act as “gatekeepers” who control the researcher’s access to the target group.
- Survey key informants regarding their experience's w/research (if any) will allow informants an opportunity to discuss prior positive and negative experiences and provide the researcher with suggestions of how to proceed.
- Conduct several focus groups in the regions with the largest concentrations of the target group, to describe the study, its value.
  - They assist with referrals by spreading word about the study.
- Invite those most interested in the research to join an Advisory Council that will meet periodically (in person and/or by conference call) to review the study, and trouble-shoot problems that come up.
  - Aids in maintaining community interest and engagement in the research process over time.
  - Work out “best practices” for recruitment of specifically targeted ethnic groups
  - Give you feedback on recruitment protocols and social marketing approaches



# Advanced Preparation

- Comprehensive training of recruitment team
  - Shadowing of senior team members
  - “hotline” or on call senior person for guidance
  - Cultural Humility training
- Beta testing of recruitment scripts and consent forms to anticipate cultural pitfalls, simplifying complicated medical concepts, and streamlining the informed consent process.
- Informed consent videos (multiple languages)

## Levels of Cultural Humility

- Individual Provider Level (practices, skill sets, experiences)
- Organizational Level (mission and vision statement, culture, demographic composition of management and staff, etc.)
- Systems Level (policies and procedures, programs and services)



# Diversify your Study Team

- Ensure you have a diverse study team
- Bi-lingual CRC's or recruiters is the gold standard.
  - Leverage translators when necessary
  - \*Ask how they'd like to receive info or be interviewed
- Critical to remember racial match does not necessarily mean they will be an effective recruiter for your study.

# Patient Education is Key

- Develop recruitment language that carefully and authentically explains the study and reassures prospective participants.
  - not being recruited because of their race, ethnicity, or gender, but because they fit the study's specific enrollment criteria
- Materials that advance patients' education.
  - E.g. Well-organized informational packet, a dedicated website, on-line videos to meet patients' different learning styles can address patients' and family members' concerns/questions.
  - Pamphlets that define "placebo," "clinical trial," and "informed consent" can also aid recruitment efforts, especially when they include customized information for various populations
- Thoroughly explain invasive measures, and WHY they are necessary
- Lean into Altruism

# Brochures for PCORI Study

## English

## Spanish



**FREQUENTLY ASKED QUESTIONS (FAQS)**

**WILL I HAVE TO PAY FOR THE SERVICES PROVIDED?**  
IT WILL NOT COST YOU ANYTHING TO TAKE PART IN THE STUDY.

**WILL I BE COMPENSATED FOR BEING PART OF THIS RESEARCH STUDY?**  
YOU WILL BE COMPENSATED \$200 IF YOU COMPLETE ALL THE SCHEDULED STUDY VISITS. ALSO, YOU WILL RECEIVE \$50 FOR A COMPLETED INTERVIEW.

**DID YOU EXPERIENCE AN UN-PLANNED HOSPITALIZATION?**

UNPLANNED HOSPITAL ADMISSIONS CAN ADD STRESS FOR YOU AND YOUR CARETAKERS.

**CONTACT US**

If you're interested in this study, please contact our Study Coordinator Rachel Henesy at (813) ###-### or rparisi@usf.edu to see if you qualify today!



**PREGUNTAS FRECUENTES**

**¿TENDRÉ QUE PAGAR POR LOS SERVICIOS PRESTADOS?**  
NO LE COSTARÁ NADA PARTICIPAR EN EL ESTUDIO.

**¿ME COMPENSARÁN POR SER PARTE DE ESTE ESTUDIO DE INVESTIGACIÓN?**  
SE LE COMPENSARÁ CON \$200 SI COMPLETA TODAS LAS VISITAS PROGRAMADAS DEL ESTUDIO .  
ADEMÁS, RECIBIRÁ \$50 POR CADA ENTREVISTA REALIZADA .

**HA TENIDO UNA HOSPITALIZACIÓN RECIENTE NO PLANIFICADA?**

LAS ADMISIONES HOSPITALARIAS NO PLANIFICADAS PUEDEN GENERAR ESTRÉS PARA

**CONTÁCTANOS**

Si está interesado en este estudio, comuníquese con nuestra coordinadora del estudio Rachel Henesy al (813) ### - ### o rparisi@usf.edu

# Community Outreach

- Macro approach to improve study participation whereby team members conduct information sessions in the community.
- Information at culturally relevant locations (e.g. barber shops, community centers/events, hair salons, religious institutions etc.).
- Build strong community relationships.
- Create a community advisory board/key stakeholders
- Multi-pronged marketing approach

# Development of a recruitment, retention and outreach core

- Bilingual/ culturally competent recruiters and outreach staff hired and trained to provide outreach, recruitment, and education
- Encourage medically underserved populations to participate in prevention studies and clinical trials
- Develop social marketing strategies that are culture and language-specific
- Educate individuals in the community about the importance of clinical research. Can connect interested community members to trials or CABs.
- Can lead to the development of a research registry for clinical trials

# Consider Practical Barriers

- How can you reduce the transportation burden?
  - e.g. provide transport, reimbursements, taxi/uber vouchers etc.
- Mitigate other obligations and time concerns as best you can.
  - e.g. provide childcare, flexibility with mode of assessment
- Balance participant payments carefully
  - Incremental increases enhance retention
- Don't let technology illiteracy become a barrier
  - Training if needed
  - Provide tech resources as part of the study protocol

# Personal relationships with patients

- Soft handoff from trusted treatment team member
  - Especially in the hospital
- Recruiters need to actively build trust:
  - “we want to partner with you and be partners in this research so that we can really find an answer”
  - “Do you like to help others”
  - Be honest and genuine
- Access to the study PI
  - Facetime, zoom, TEAMS etc. to access PIs when patients have questions.
  - Video message from the PI (no one is as excited about your study as you are)

# Personal relationships with Staff

- Build recruitment into the hospital/organization milieu
- Get staff excited about this study, they will help recruit
  - posters and white boards where staff congregate to highlight on-going studies and study contact
  - need to remind staff often about study opportunities
  - use monthly meetings with hospital staff to follow up on recruitment progress
  - Bring food!!!!!!
- Equip staff with marketing materials and information in multiple languages
- Sub-contracts with hospitals/recruitment sites

# Overview of Strategies

- Build Trust
- Diverse and competent research team
- Culturally relevant multi-media marketing
- Referrals from a trusted source
- Community advisory board

# Resources

- [The Recruiting Older Adults into Research \(ROAR\) Toolkit](#)
- [The NIA Health Professionals Information website](#)
- [Points to Consider about Recruitment](#)
- [Enhancing the Diversity of Clinical Trial Populations — Eligibility Criteria, Enrollment Practices, and Trial Designs Guidance for Industry\(link is external\)](#)
- [CEAL website](#)



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# Questions and Conversation



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