ISSUES AND CHALLENGES ASSOCIATED WITH RECRUITMENT AND RETENTION FOR HEALTH RESEARCH

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Objectives

- Outline the issues that affect recruitment and retention of participants to research.

- Identify solutions to these issues

- Provide examples of solutions
Challenges to Retention and Recruitment

• Attitudes towards:
  – Research
  – Researchers
  – Institutions
  – Universities

• Research knowledge and literacy

• Outreach strategies and engagement
Basic Requirements for Success

• Flexibility to adjust study recruitment to account for differences in location, behavior, media, technology use, etc.
  – Basic knowledge of a client socio-cultural position

• Communities and participants have to be met with openness and acceptance.
  - Right staff, materials and approach

• Long lasting partnerships are helpful.
  – The challenge for researchers is to work in such a way that trust is developed and maintained.
Basic Requirements for Success

• Make the ask

• Know your audience

• Go where they are

• Build the relationship
Make The Ask

• Staffs need to come from a variety of backgrounds;

• Staff needs to have people skills.

• Maintained continuing contact with study participants;
  – Birthdays, holidays, Facebook and twitter sites that were fun.

• Case management model – a source of referral and support.
Make the Ask

• Health provider connections and support

• Endorsements can be important – political, health, business, church, community

• Right media for the market – racial & ethnic minority media; right frequency – Are you talking to me?

• Right incentives, including non-cash incentives
Know Your Audience

- Education, research literacy
- Media preferences
- Region of the country
- Group diversity
  - Immigration status
  - Level of acculturation
  - Identity
- Gender, age and generation
  - Technology use
  - Media
Learning About Your Audience: The NCS Experience

1. PARTICIPATION WITH AND WITHIN THE COMMUNITY
   – Carving out a respected place in the community for the study through awareness raising efforts.

2. MIRROR THE COMMUNITY
   – The makeup of the NCS staff mirrors the demographics and norms of the community;
   – Community norms and demographics should be considered for mass communication and outreach, screening and recruitment, and when maintaining continuous contact with study participants.

3. TRAINING
   – Consistent relationships with study participants and staff who were responsive and informed often assisted in participants’ ability to see as trustworthy.
Go Where They Are: CECCR

• We go where people are everyday;
• Identify in ZIP codes with racial/ethnic, low-income residents.
  – health centers,
  – laundry mats,
  – beauty salons & barber shops

• Neighborhood Voice Mobile Unit (NVMU)
  – The NVMU is a shuttle-type vehicle customized for research
  – Allows engagement in the communities.
Go Where They Are:

Survey of Multicultural Factors Affecting African American Colorectal Cancer Screening

- Effective call lists
  - Targeted list sample, created using random digit dial (RDD) generated lists
  - Matched to a market research data
  - Developed to assure that proportional to the geographical distribution of the African Americans
  - Used a separate RDD list in calling to reduce biases produced by a listed sample.
Go Where They Are: Feasibility Study

- Internet use is widespread and could be a channel to reach and disseminate health information to AA men;

- There are disparities in internet use and limited literature exists on how to best address this divide.

- Our data suggest that disseminating information online is not a very effective way to reach older African American men, with limited education.

- We do not recommend using websites among this population,

- Email was effective in getting participants to the website, even though they expressed a preference for phone messages.
Build the Partnership

**Implemented** a community based participatory research training program for community members.

**Promoted** the role of underserved populations in research by enhancing the capacity for community based participatory research.

**Bridge** Washington University in St. Louis (WUSTL) researchers and community based organizations and community health workers serving the St. Louis Greater Metropolitan area to address health disparities.
Community Research Fellows Training Program (CRFT)

• Train community members to become good consumers of research.

• Understand how to use research as a tool in improving health outcomes in communities.

• Increase community members understanding of how to work with academic researchers.
17 Multidisciplinary faculty have trained four cohorts (122 community members) through a semester long public health research training course.

Created a pool of trained community members who collaborate with academic researchers and other health practitioners on community research advisory boards, councils and institutional review boards.
Patient Research Advisory Board (PRAB)
**Goal and Objectives**

**The St. Louis Patient Research Advisory Board (PRAB)**

1. Serve in an advisory role to academic researchers on issues of community engagement, building trust, and ethical considerations of research and study design.

2. Provide a forum that allows for mutually beneficial communication between community stakeholders and academic researchers on meaningful, relevant clinical concerns.

3. PRAB informs, guides and reviews grant proposals.

4. PRAB will fosters academic community linkages and disseminates information about clinical research findings pertinent to the community.
Questions?