Laying the Foundation for Community Research
HPTN CWG Community Forum

Kemi Amola MA, LPC, NCC
University of North Carolina at Chapel Hill
AIDS Clinical Trials Unit
Presentation Outline

• Network Overview
• Study Overview
• Roles and Responsibilities of the Clinical Research Site (CRS) in Laying the Foundation for Community Involvement
Network Overview

• The HIV Prevention Trials Network (HPTN) is a worldwide collaborative clinical trials network that develops and tests the safety and efficacy of primarily non-vaccine interventions designed to prevent the acquisition and transmission of HIV.

• The HPTN has 80 research sites in 13 countries, Botswana, Brazil, China, India, Kenya, Malawi, South Africa, Tanzania, Thailand, United States, Uganda Zambia, and Zimbabwe.
Study Overview

Primary:
- To estimate HIV incidence in a cohort of women at risk for contracting HIV in the US and to evaluate the feasibility of enrolling and following a cohort of these women

Secondary:
- Describe sexual behaviors, substance use, prevalence of domestic violence and mental health
- Explore facilitators and barriers to HIV testing among men
Design

- Enrollment of 2,000 women across 10 communities, followed over 6 to 12 months
- Each participant completed a computer survey and received HIV testing at each visit
- A subset of women also participated in an individual interview or focus group

Key:
- $\text{X}$ = enrollment visit
- $\text{ }$ = follow-up visit
- $\text{ }$ = retrospective
- $\text{ }$ = prospective
10 distinct communities within 6 geographic locations
Recruitment

- Venue-based sampling in locations frequented by women who live in study census tracts/zip codes
- Suitable venues and recruitment times determined by ethnography
- Efficient, rapid accrual
- Community engagement is key!
Laying the Foundation for community Involvement

Wake County NC
Durham County NC
R.E.S.P.E.C.T.

Removing Barriers
Expressing Commonalities
Seeking Mutual Benefit
Presenting Yourself Often
Expecting the Best
Coming Through with Promises
Thanking Them!
The motives, sensitivity and experience of the research team was a key factor.
Community Sensitivity

• All staff received training on safety, cultural competency, and other nuisances of working in the identified communities
Community Involvement

• Emphasis was placed on integrating ourselves into the community before we conducted any study activities
We began by engaging the communities in which our research was going to take place by conducting surveys to identify stakeholders.
Type of Stakeholders

- Once identified, we divided the Stakeholders into three categories:
  - **Organizational** - Agencies who work with identified communities
  - **Community** - Organized leaders who live in the identified communities
  - **Participant** – Informal leaders who may be potential participants in the study and had buy in with other potential participants
CAB Member Presentation
HPTN CWG Community Forum

Caressa M. White MA
University of North Carolina at Chapel Hill
AIDS Clinical Trials Unit
Presentation Outline

• CAB Structure
• CAB Responsibilities for Laying the Foundation for Community Involvement
• Novel Approaches to CAB Utilization
CAB Structure

The CAB currently consists of 15 members:

1 PI
4 UNC Staff
11 community members

Demographics

- 5 women/6 men
- 5 African American/1 Nigerian/5 White

Meetings

- Every other month at Dr. David Wohl’s (Principal Investigator of the ACTU) residence.
CAB Responsibilities

• **Gaither Information for Community Profile**
  - Community Health Assessments
  - Community Diagnosis

• **Educate and Train**
  - Reviews protocols and informed consents to ensure materials are linguistically and culturally competent

• **CAB Development and Recruitment**
  - By-laws and Mission Statement
  - Printed media
  - Short term community collaborative councils
Novel Approaches to CAB Utilization

Health on Wheels: Moving Health Forward

- Approach to extend research and health initiatives beyond the clinic walls directly to the community
Thank You

Questions and Answers