

Community Engagement at CUMC (for research):

The CALME & CHUM
Experience
and what the I²=CTR Will Bring

Why Engage the Community

- Consumers: Service Delivery
- PR and Government Relations
- Research
 - Recruitment and Retention
 - Research that benefits the community
 - Community as part of Research Team (CBPR)

What is a community?

- Populations that may be defined by: geography; race; ethnicity; gender; sexual orientation; disability, illness, or other health condition;
- Groups that have a common interest or cause, such as health or service agencies and organizations, health care or public health practitioners or providers, policy makers, or lay public groups with public health concerns.

Community-based organizations

- Organizations that are members or representatives of the community
 - State or local governments
 - Educational institutions
 - Advocacy organizations
 - Health delivery organizations (e.g. Hospitals, FQHCs)
 - Health professional associations
 - Non-governmental organizations
 - Tribal governments and colleges

CU MISSION STATEMENT

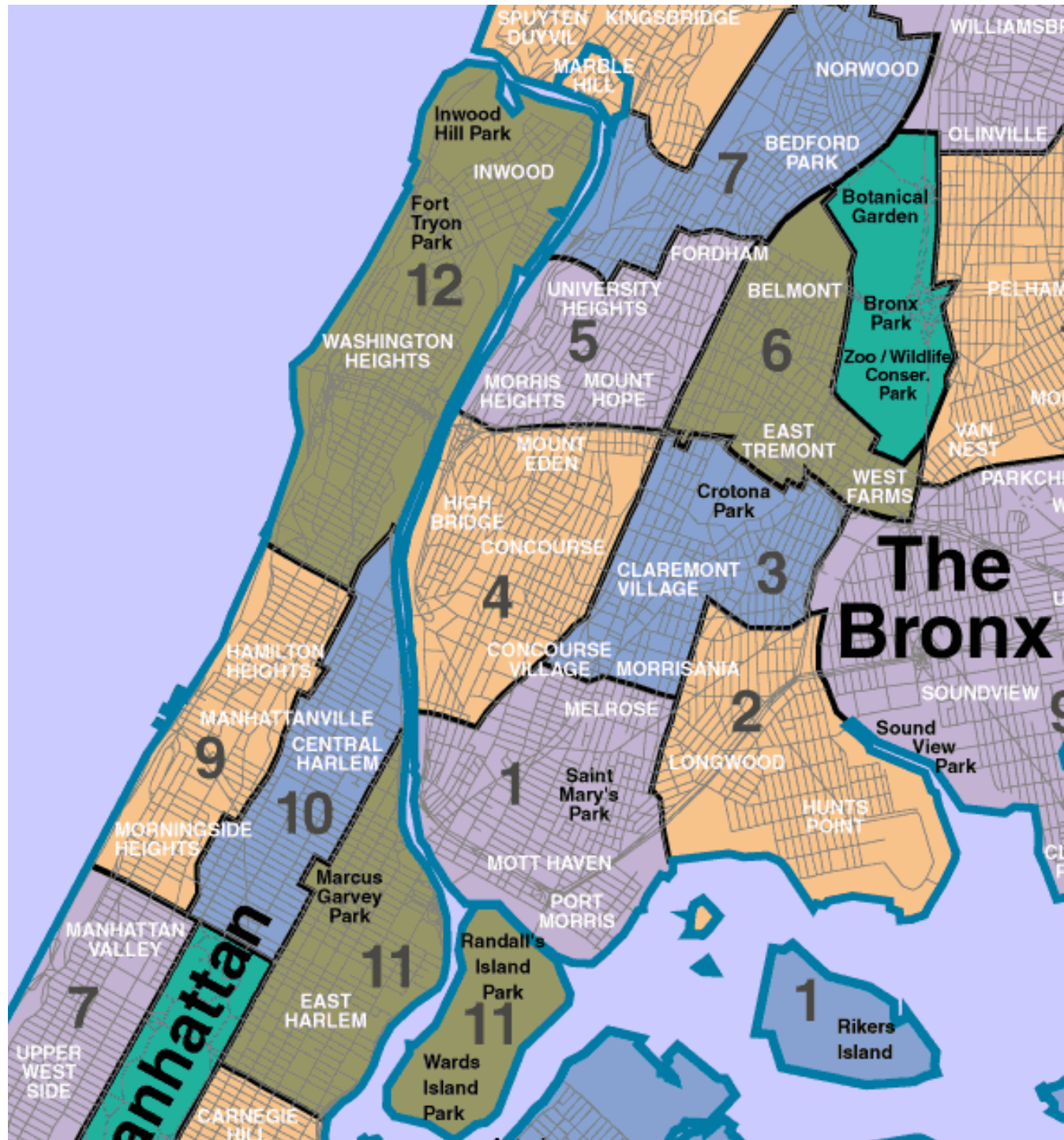
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- Columbia University is one of the world's most important centers of research and at the same time a distinctive and distinguished learning environment for undergraduates and graduate students in many scholarly and professional fields.
- **The University recognizes the importance of its location in New York City and seeks to link its research and teaching to the vast resources of a great metropolis.**
- **It seeks to attract a diverse and international faculty and student body, to support research and teaching on global issues**, and to create academic relationships with many countries and regions. It expects all areas of the university to advance knowledge and learning at the highest level **and to convey the products of its efforts to the world.**

CUMC

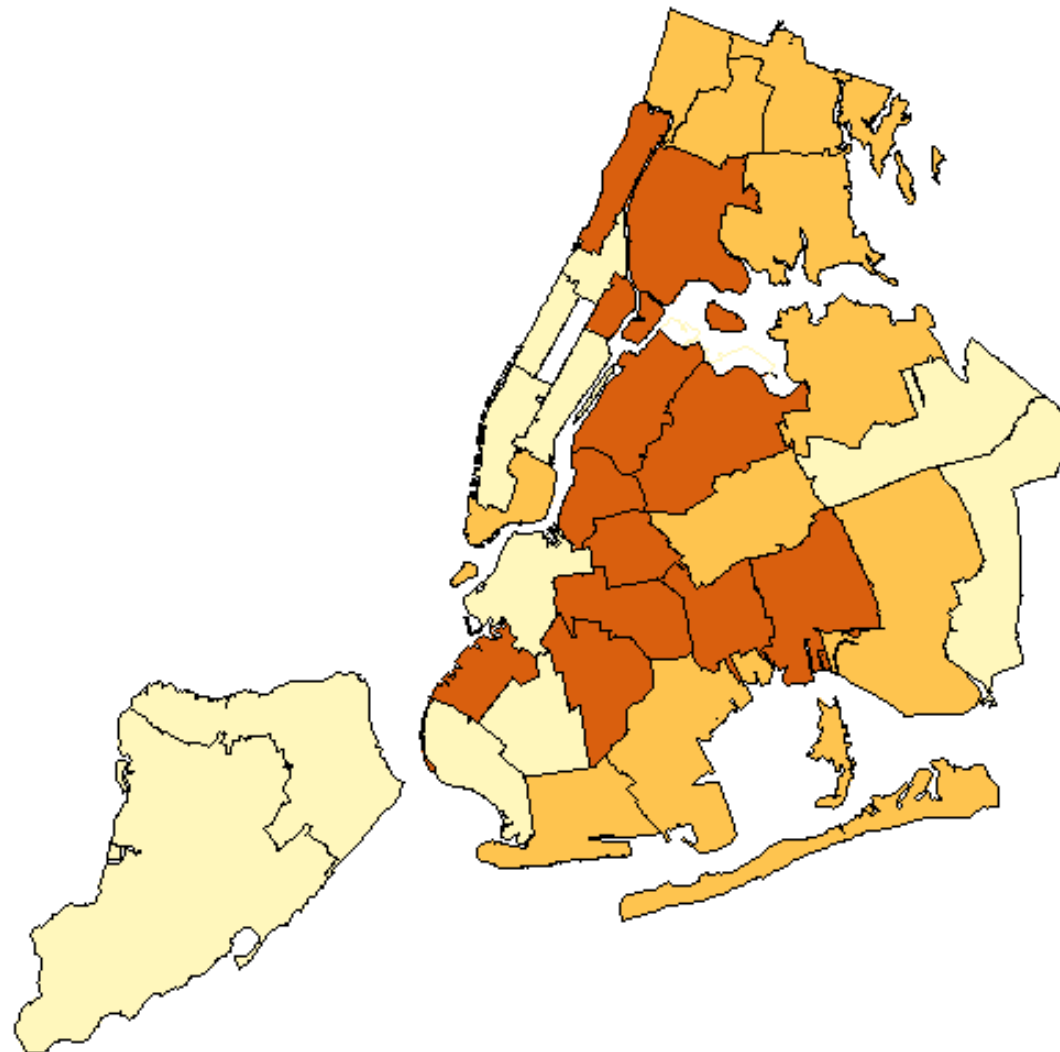
- Government & Community Affairs represents the interests of Columbia University Medical Center before the federal, state, and city governments
- This office also develops and implements programs with the communities surrounding Columbia University Medical Center and serves as the liaison between the Medical Center and the external community
- (give other examples community CUMC, Rock, UCLA)

Future CHUM CAC

- Community Engagement/Outreach Core (optional)
- Each activity within this core should address a research question rather than simply provide a service



Percentage with no health insurance by neighborhood , NYC Community Health Survey 2004
(To obtain the name and value for any given neighborhood, move your cursor over the map or see the table below)



Percent of Total Frequency 7.30 - 13.86 14.45 - 19.41 19.54 - 32.67

Bureau of Epidemiology Services, NYC DOHMH

Community Engagement at CUMC

- CUMC Office Gov. & Community Affairs
 - Frommer /Harris
- NYPH
 - Polf/ Morik
- CU
- Babies Hospital
- ? Dentistry, SPH, Nursing

CUMC Gov & Community Affairs

- Comprehensive advisory and technical assistance for the development of institutional community partnerships
 - Program development, community relations, grant writing, strategic marketing planning, development and implementation for healthcare and social marketing campaigns, targeted media campaigns for community outreach programs
- Quarterly technical assistance workshops to community-based organizations
 - Marketing, grant writing, fund raising, board development, and program evaluation

Why Should Investigators be Interested in Community Engagement

- Need for recruitment and retention
- Increasing Political Advocacy for Community Participation in Research: NIH Roadmap
 - Hispanic Community Health Study
 - Clinical Translation Science Award
- Some areas will be mandated to have community input / collaboration
 - genomics
- Increasing Community Sophistication

community-based research

- Research conducted in a community as a place or setting
- Research primarily driven by the academic institution
- May address areas of importance for community
- Limited involvement of community members
 - Study subjects
 - Recruiters, community liaisons, RA's

COMMUNITY BASED PARTICIPATORY RESEARCH (CBPR)

- *Collaborative approach to research that **equitably** involves all partners in the research process and recognizes the unique strengths that each brings*
- *Begins with a research topic of importance to the community*
- *Has the aim of combining knowledge with action and achieving social change to improve health outcomes [and eliminate health disparities]*

Mandates

- Participatory models of research, in which communities are actively engaged in the research process through partnerships with academic institutions, have become central to the national prevention / disparities research agenda
- Calls by IOM, NIH, CDC, AHRQ.....
- Increasing Evidence Base for CBPR

PRINCIPLES OF CBPR

- *Facilitates collaborative, equitable involvement of all partners in all phases of the research.*
 - collaborative partnership in which all parties participate as equal members
 - share control over all phases of the research process,
 - e.g., problem definition, data collection, interpretation of results, and application of the results to address community concerns

CBPR

- Involves a collaborative partnership in a cyclical, iterative process in which communities of identity play a lead role in
 - identifying community strengths and resources
 - selecting priority issues to address
 - collecting, interpreting, and translating research findings in ways that will benefit the community
- Emphasizes the reciprocal transfer of knowledge, skills, capacity and power.
- The focus of the partnership is driven by issues and concerns identified by members of the community of identity.

Challenges: Community Distrust of AHCs

- Traditional mistrust of research
- Guinea Pig phenomenon
- Abandonment
- “Not in loop”
- Failure to carry out with policy / interventions
- Not sharing \$\$\$\$\$

Challenges

- Academic Distrust of Community
 - Public relations
 - Politics
 - Fiscal Integrity
 - Foreign Culture
- Community Capacity to conduct Research
- \$\$\$\$\$\$ / Indirect issues
- Evaluation

How did community participate?

- Intervention & Analysis
 - Who were community representatives?
 - Why/how were they chosen?
 - What roles did they have in design, implementation, analysis & interpretation?
 - What safeguards were used to ensure data integrity & methodologic rigor?
 - How was community perspective incorporated into analysis & interpretation?
- In CBPR grants- resource sharing

RESOURCE CENTERS FOR MINORITY AGING RESEARCH

CUMC RCMAR= Columbia Center for the
Active Life of Minority Elders (CALME)

- 1) Conduct research on health of minority
elders
- 2) Enhance diversity of researchers in
minority aging health

5 Cores

- Administrative
- Investigator Development (pilot awards)
- Methods and Data
- Measurement
- Community Liaison

Community Liaison Cores

- Develop and maintain relationships with minority group members and minority community-based organizations (CBOs)
- Work with CBOs to foster acceptance in minority communities for participating and remaining in research projects.
- Facilitate interaction among minority community members, leaders, and CBOs, with researchers planning studies involving the host communities.

CALME CLC Core

- WHICOA Advisory Board
 - Peralta is Co-Chair
 - CAB- meets once a year
 - Able to provide input to other CUMC investigators
- Monthly Community Cable Show
- Quarterly Community Newsletter
 - Both vehicles to explain your work to community
 - Recruiting
- Senior Center Health Education Lecture Series
 - 357 so far
 - Often part of recruitment
 - 80% Bilingual
- Medical / Nursing Student Screenings/ Education
- Community Research Information Day

Why is Washington Heights and Inwood in the bottom 10 of 41 NYC neighborhoods in Access to Care?





Co-sponsoring of community partner event
(WHICOA) August 17th 2005.
Political Candidates Forum with translation
for Latino seniors.



Community Research Information Day



DEVELOPMENT OF COMMUNITY-BASED PARTNERSHIPS IN MINORITY AGING RESEARCH

The Resource Centers for Minority Aging Research (RCMAR) initiative was established in 1997 and currently includes six centers across the United States. The model of community engagement developed by all the RCMARs is Community Based Participatory Research (CBPR). This supplement explores the diverse methods of partnership building in each RCMAR and highlights some of the successes and challenges encountered in CBPR. Two articles focus on how the CBPR infrastructure facilitates the conduct of research in minority communities. Two other manuscripts discuss the unique experiences at these RCMARs in the CBPR partnership development process. The final paper describes the mentoring processes used at each of the RCMARs for both junior academic investigators and community members. We conclude that CBPR is a difficult and long-term process requiring substantial buy-in and commitments from both the academic and community partners in a continuous and evolving collaborative partnership. (*J Am Geriatr Soc* 2007;17(suppl 1):S1-3-S1-5)

Key Words: Community-Based Participatory Research, Minority Groups, Ethnic groups, Health disparities, aging

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The Resource Centers for Minority Aging Research (RCMAR) initiative was established in 1997 by the National Institute on Aging as part of its overall effort to reduce health disparities between minority and non-minority older adults. The RCMARs were mandated to include a community liaison core (CLC) whose mission was to develop and sustain mutually rewarding, productive, and culturally appropriate partnerships between academic institutions and their communities. In the second round of the RCMAR initiative, six centers across the United States were funded in Los Angeles, San Francisco, Colorado, Michigan, New York City, and South Carolina, as was one coordinating center.

The model of community engagement developed by all the RCMARs was that of community-based participatory research (CBPR), which is a collaborative approach to scientific inquiry conducted in equitable partnerships between academic researchers and the community being investigated.¹ In CBPR, community members and other key community stakeholders have the opportunity to be full participants in each phase of the work, including the conception, design, conduct, analysis, interpretation, and dissemination of results.² This equitable partnership is the hallmark that distinguishes CBPR from traditional community-based research in which academic investigators maintain most of the control with respect to research question, study design, data analysis, and dissemination of findings. CBPR improves the quality and impact of research by generating better informed hypotheses, developing more effective interventions, and enhancing the translation of the research.³ The ultimate benefit from CBPR is a deeper understanding of a community's

unique circumstances and a more accurate framework for testing and adapting best practices to community needs. Funders are increasingly recognizing that the CBPR approach is particularly attractive for academic and public health professionals in the areas of health promotion, disease prevention, and health disparities.⁴

Despite the promise of CBPR, numerous challenges have arisen, not the least of which is the partnership development process itself. To increase the knowledge base in minority aging CBPR, in 2004, the CLC cores of each RCMAR organized a workshop at the annual conference of the Gerontological Society of America. The aim was to explore the diverse methods of partnership building in each RCMAR and highlight some of the successes and challenges encountered in CBPR. In this supplement, we expand on the descriptions of five of the projects presented at that workshop.

The first two papers in the series are examples of how having a CBPR infrastructure can greatly facilitate the conduct of research in minority communities. The first study describes the Colorado RCMAR's focus on the American Indian community. Unlike the other RCMARs described in this supplement, the Colorado site defines its community by race rather than by geography. Noe et al examined the potential of the CBPR approach for increasing recruitment of American Indians into research studies. The finding of these investigators, that adding CBPR components to the study design (ie, active community involvement and having an American Indian as principal investigator) increased the recruitment of American Indians into research, is a contribution to the CBPR literature. This study

CALME Services to Investigators

- Letters of Support
 - CALME
 - CBOs
- Recruiting at Senior Center
- Partnership Development with Senior Centers

CALME CLC Summary

- Bi-directional mutually beneficial relationship
- CLC not research focused so FUN!!
- Others core have the hard work
- Work of core helped many other researchers
 - Good will it creates with senior groups
 - Help in recruitment

Future of CALME CLC

- Community Liaison Core (Optional Core)
- The CLC is not intended to be a service function of the RCMARs for the targeted study communities. It is a science-generating Core.
- Become leaders in the science of recruitment and retention of diverse group members for scientific research
- Disseminate scientific information regarding techniques for recruiting and retaining minority research participants
-

RFA-AG-07-005



The Columbia Center for the Health of Urban Minorities (CHUM)



Consists of Nine Cores

- Administrative Core
- Research Training Core
- Community Action Core
- Health Disparities Core (Cultural Competency Core)
- Five Research Cores (Access to Care, Cardio-vascular Disease, Mental Health, Injury Prevention, Diabetes)







Core 2 – Training Core 2005 Summer Research Interns



Community Action Core

- (1) Planning Council composed of CBO leaders who will collectively develop, evaluate and modify approaches to community-based health promotion/disease prevention research
- (2) Creating an infrastructure to enhance the capacity of community-based organizations to become active participants in, and initiators of, research projects;
- (3) Improving the capacity for academic researchers to understand the basic tenets of community-based participatory research;
- (4) Enhancing opportunities for bi-directional, meaningful, and respectful communication between community partners and academic researchers.
- 3 CAC PI's later....

Community Engagement

- Cable Show
- Community Newsletter
- Community E-Newsletter
- Involve community in cores
 - Community tours
 - Team building community project
- Help in other areas
 - Talks, resources,

New Specific AIMS: Integrate CBPR into each of CHUM Research Cores/ work of investigators

- Partial Success (depends on core leaders/ investigators)
- Some cores already doing CBPR
 - Injury Prevention
- Most were doing excellent Community Linkages and continue doing so
 - Access core, Diabetes Core
- Most were not doing and will not do CBPR
 - Impractical to do CBPR in secondary data analysis
 - Multi site NIH type Clinical Research hard add CBPR
 - Highly Successful Investigators do not need to do CBPR

New Specific Aims

Community Planning Council

- Leaders of 5 CBOs
 - Alianza, Dom Womens Dev Center, NMPP, NMIC, WHICOA
- Did not want to be Community IRB
 - Not help with review of protocols for community appropriateness, cultural issues, translations, etc
- Focus activities that would provide resources, help developing their own CBO's
- Very interested in “true” research partnerships
- Very interested in developing their own capabilities/ infrastructure
- Did not want to be paid to be on CAC

Develop Partnerships between CUMC Investigators and CBOs

- CBPR Clearing House / Match making
 - Partial success
- Investigators present to planning council they decide to participate
- Often approach for recruiting after study funded
 - Mothers using cocaine
 - Subjects for HIV at risk studies
- Some success at investigators approach at start and share resources

Community Planning Council



Community Planning Council



Do CBPR

- 2 R01 for one time RFA's that got "respectable" low 200's
 - CBOs very good idea, will not get anything in writing
 - Need to do all subcontract work for them
- CAC Pilot Awards- RFA
 - CBO proposal with CUMC investigator as collaborator
 - Often CUMC investigator not very involved
 - Evaluated using NIH type criteria
 - Use money for training
- Needed extensive help
 - Ended hiring CUMC based person to work with each CBO's proposal
 - NIH format, study design, IRB application

4 awards

- Senior Center Based Walking Club
- Outcomes of CQI intervention on client flow
- CHW led DM education for mothers with gestational diabetes
- Qualitative study on community perceptions of depression and genetics



Get more CBPR grants

- RO1 RCT of CHWs of Framingham Risk Scores
- CHUM renewal was PO1 like- needed 3 R01's, two are CBPR like
 - RCT of CHWs on Diabetes
 - Senior Center Based Motivational Interviewing on HTN

NYS DOH OMH

- Using community based CHWs to recruit into cancer clinical trials
- Get 15 CHWS HIPAA/ IRB certified
- Train them on recruitment 101
- See if they can include recruitment as part of their ongoing activities at CBO

Infrastructure Development at CBO

- Many are IRB/ HIPAA certified have NIH bios
- Budgets, NIH format
- Totally understand how hard grant process is
- Have some concept of what we mean by research
- Some programmatic developments

Lessons Learned

- Even when have trusting relationship CBPR is hard
- CBOs interested in developing CBOs
- Willing work on “research” if they can see some benefit for them
- Need to do most of leg work for them

Future CHUM CAC Core

- Community Engagement/Outreach Core (optional)
- Each activity within this core should address a research question rather than simply provide a service

CTSA

- Institutional Clinical and Translational Science Award
- Assist institutions to forge a uniquely transformative, novel, and integrative academic home for Clinical and Translational Science
- Serve as a magnet that concentrates basic, translational, and clinical investigators, community clinicians, clinical practices, networks, professional societies, and industry to facilitate the development of new professional interactions, programs, and research projects.

CTSA: Community Engagement

- Foster collaborative partnerships and enhance public trust in clinical and translational research, facilitating the recruitment of research participants from the community.
- Engagement of both the public and community providers, and establishing long-term relationships with community-based groups such as voluntary and professional organizations, schools, women's health groups, faith-based groups, and housing organizations, might be required.
- Community outreach and cultural sensitivity training for institutional clinical and translational researchers,
- community and provider education and outreach,
- Expose scholars and researchers to population and community-based research methods



IRVING INSTITUTE
FOR CLINICAL AND TRANSLATIONAL RESEARCH

Columbia University CTSA External Advisory Board Meeting



COLUMBIA UNIVERSITY
MEDICAL CENTER

NewYork-Presbyterian
The University Hospital of Columbia and Cornell

Community Engagement Resource

Bernadette Boden-Albala, PhD
Raphael Lantigua, MD

Community Engagement Resource **AIMS**

Enhance the quality of population and community-based research ongoing at CUMC

- *training, mentorship, grant awards*

Effectively communicate with the community in order to foster research of mutual benefit to both university and community.

- *research registry, community resource center, community research days*

Facilitate the integration of a community-based provider network

Community Engagement Resource

- **Co-Directors:**
 - **Rafael Lantigua, MD** - Medical Director Associates in Internal Medicine
 - **Bernadette Boden-Albala, MPH, DrPH** - Ass't Professor of Neurology and Sociomedical Science
- **Key Members**
 - **Dr Olveen Carrasquillo, MD** - Assoc. Professor Clin Medicine and Health Policy and Management
 - **Suzanne Bakken, RN, PhD** - Professor of Nursing and Bio-informatics
 - **J. Thomas Bigger, MD** - Professor Medicine and Pharm, Medical Director Clinical Trials Network
 - **Joyce Moon Howard, PhD** - Asst Prof of Socio-medical Science.
 - **Nelson Peralta, MD** - Project Coordinator for Center for Health of Urban Minorities
 - **Sandra Harris** - Ass't Vice President for CUMC Office of Government and Community Affairs

Community Engagement Resource

- ***Community Newsletter***
- ***Cable TV Programs***
- ***Community Research Day at CU***
- ***Establishment of Community Research Database***
 - Integrate into larger CTSA database
 - Identify community via check list of key words and methodologies
 - Links for evaluation of utility
 - Challenge to identify all community research and facilitate collaborations
-

Community Engagement Resource

Involvement of Community Docs in Research

- Specific mentorship and training activities tailored to community-based practitioners, and others who are not considered CUMC researchers.
- Community healthcare providers trained in GCP, HIPPA and NIH bio
- ***Community Research Needs Assessment***
 - Needs Survey created on survey monkey
 - population identified - ACNC, AP, ED, and Voluntary MD
- ***Design and implementation of first CER course***
 - Tentative Plan (4 hour course with GCP certification)
 - Utilize ethics leadership for GCP lecture
 - Initiation of clinical research realities discussion
 - Schedule for Saturday in June-

Enhancement of training in community-based research for all CUMC investigators

- Training and Mentoring of Community-Based C/T Investigators
- Certificate based annual training course in Community Based Research
- CBPR Course
- ***Community Researchers Retreat***

Community Engagement Resource

- ***CER community advisory board.***
 - CUMC wide CAB for all CUMC Projects
 - ? Community IRB
 - Three levels of function
 - IICTR CAB
 - Letters Support /CAB like function for others
 - CBPR for few
 - Challenge to get buy in from CBOs
- Pilot Awards to Comm groups

Community Engagement Resource ***CER Facility***

Storefront Real Estate- ? 180th Forth Wash, 3,000 sq feet

- Irving's \$5 million?
- Staffed 1 coordinator, 50% Research Nurse
- Meetings, Lectures, Web based activities
- ? Services versus research center
- Interviews, clinical exams
- ? Bloods- Comm CRC

Community Engagement at CUMC

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Experience

and what the I²=CTR Will Bring