Recruitment and Retention of Community Participants

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Presentation for RMATRIX
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University of Hawai`i
Welcome and Introductions

- RMATRIX Program
  - Mahalo to Drs. Jerris Hedges, Dean, JABSOM, and PI, Bruce Shiramizu and Todd Seto, Professors and CoPIs
  - Also, Drs. Jillian Inouye and Merle Kataoka-Yahiro, Professors, SONDH, and Community Education, RMATRIX
  - Mr. Brad Jones, PBRC

This a recorded session. Please check that you agree to this—left link
Questions? Comments?

- During session: Chat Space
- Following session: Email me at cbrowne@hawaii.edu
- Immediately following session: Dr. Merle Katohiro will ask for evaluative comments
Today’s Learning Objectives

- Discuss community-based recruitment and retention strategies and approaches
- Provide rationale for minority participation in research
- Discuss barriers to minority recruitment
- Provide examples of successful community-based models and approaches
Scientific progress depends on:

- Successful recruitment and retention of study participants
- Efficient and effective recruitment and retention strategies

Can be labor intensive but pivotal to success of achieving key research objectives

Ohio State University, Center for Clinical and Translational Science, 2012
Recruitment and Retention (R & R):

- A good R & R plan can help design **first touch points** with the community & share best practices to help researchers achieve recruitment/retention goals.

- Most successful approach to recruitment—a **combination of multiple tools** and strategies.

- Use **best practices unique to study**—examples: brochures, flyers, mailings, surveys, posters, newsletters and appointment reminder strategies for IRB approval.
Overarching goal: Elimination of social, economic and health disparities among different segments of US population—and yet disparities continue to exist

NIH Guidelines For Research: All NIH Funded Research Must:

- Provide scientific evidence relevant to all segments of the population
- Elicit information about M & W and individuals from diverse racial and ethnic groups
- Examine the differential effects of treatment of gender, racial, and ethnic groups in clinical trials when possible
A focus on Racial/Ethnic and Minority Populations:

Known differences in disease rates, medication compliance & response, and morbidity & mortality suggest need for increased minority participation in research:

- Learn more about disease processes in different populations
- Discover new treatment modalities
- Learn from the community new strategies that integrate culture, place, & other key variables
The Science of Recruitment & Retention for Community Studies

Theoretical and Conceptual Frameworks

- **Inclusive approaches** to R & R (knowing and understanding your community (focus of research))

- Know **cultural-historical background** (values, beliefs, identifies and meanings attached to experiences) & **sociopolitical conditions** (economic status and access to goods and services) of diverse groups should guide strategies.
Three Examples of R & R Models/Approaches

- CBPR—Focus on Community
- Community Outreach Model
- Institutional –Focus on Research Barriers
Community based Participatory Research (CBPR) Framework

- **Communities** -- knowledgeable of their values, beliefs & perceptions about research—can help formulate research recruitment strategies
- **Collaborative** & equitable approach
- Integrates knowledge with action, promotes co-learning, addresses health from an ecological perspective, disseminates findings to all partners, and commits to long-term relationships
Recruitment & Retention of Minority Participants: Health and Retirement Study (also CBPR)

- **Comprehensive model**: outreach & education programs with a marketing approach
- **Marketing approach**: 6 guiding principles: product, price, place, promotion, participant, & partners
- **Oversample strategies** employed by HRS successful in identifying and recruiting
- **Interviewer training**—essential in overcoming barriers in willingness to participate
Community Outreach Model: Healthy Aging in Neighborhoods of Diversity Across Lifespan Study

1. Multilevel & multifactorial R & R method informed by evidence from literature on barriers to recruitment & community feedback, and community advisory board

2. **Clear communication** of the research hypothesis directly related & relevant to community

3. Focus: Providing **direct benefit** for participants
Institutional Research Model: Diabetes Program for Indians

- Retention in Cardiovascular Risk Reduction and Diabetes Study
- Contribution of site specific characteristics to retention (what worked):

  - Medium sized user populations—**large numbers** of participants, **mix** of younger & older staff, male & female, & **higher levels of professionalism**

  - Speaks to: issues of **access**, optimal availability of **resources** (i.e., time, expertise), **program presence**, & **credibility and authority**.
Determining Target Sample Sizes for Population Subgroups

- Meeting guidelines for inclusion?
- Ask: What is the racial/ethnic distribution of the disease, problem issue that is being targeted?
- What proportion of the minority community in Hawai`i is affected by this disease?
- What is the minority representation overall in this target catchment area?
Ultimate Goal for Minority Representation for your Study:

- Depends on your research question
- Affected by what you are targeting in your study
- Focused on prevention vs. Treatment?
What do we know about R/E Community Research Attitudes?

- Studies on African Americans: perceived social differences b/w researchers and participants
- Not enough information on benefits
- Distrust of medical establishment and research (e.g., Tuskegee study)

Objective: Investigate **barriers** to medical research (MR) participation that involves API populations in Hawai`i

**Sample:** 50 (27 Filipinos, 23 Hawaiian/Pacific Islanders) in 5 sites

**Design:** Nine **focus groups** with ethnically matched moderator: explore feelings, problems, & recommendations about medical research
Findings & Reasons for Non-Participation

- 12%: would not participate in a clinical study
- Agreement that research is important
- Filipino participants: more optimistic about safety & value of MR
- Hawaiian groups more hesitant & fearful of MR
- Reasons for non-participation: negative feelings about purpose & intent of MR, and language & cultural barriers.
Suggestions: Improve Recruitment

- **Improve awareness** of process of informed consent & research safeguards
- Commit to **return results** to study participants
- **Increase numbers** of professionals and researchers culturally/linguistically matched to community
- Improve people’s understanding of **benefits** to family and community

Strategies for Maximizing Community Sample—Develop a Recruitment Plan*

1. Build relations and commit to reciprocity
2. Detailed understanding of the population being recruited
3. Hire and train recruitment staff that represent and/or have good relations with target population
4. Recognize potential barriers and develop plans to address them
5. Pilot test recruitment strategies

NIMH, nd. Points to consider about recruitment and retention while preparing a clinical research study. Washington, DC: NIH/NIMH.
1. Build Relations and Commit to Reciprocity (Community Engagement)

- Identify and engage desired community
- Develop/maintain/strengthen relationships (CBPR ideals)
- Develop/seek strategies to engage different communities before and during your study
- Identify any ongoing collaborations/partnerships in your institution
- Determine what participating communities receive for study involvement
Suggestions:

- **Reciprocity**: Make new friends & relations
- Establish a community-based **advisory** board
- Consider qualitative methods to **assess** needs and preferences of potential participants
- Think before, during and after about your **dissemination** approaches that are useful to the community
2. Develop detailed knowledge of target population

- Review social science, medical, epidemiological literature (get data grounded).
- Gather information on cultural values, beliefs, practice & behaviors relevant to study participation (recognize diversity in beliefs about health, illness, treatments, etc.)
- Pay attention to other variables; e.g., SES, acculturation
- Build a trusting and respectful relationship PRIOR, DURING, AND AFTER the study
Suggestions

- Provide **technical assistance** (TA) to communities to build relations and honor reciprocity

- Commit to **diversity** on your research team

- Pay attention to **R & R** efforts

- Review your **IRB** procedures for ease of understanding
3. Hire and train diverse recruitment staff

- Commit to recruiting from target populations
- Take time to explain purpose and rationale of study—get them on board
- Commit to bi-directional learning
- Help with events, serve on boards, trainings etc.
4. Recognize Potential Barriers & Develop Strategies to Address

- **Participant Barriers**: Sociocultural barriers—language, fear/mistrust/cultural beliefs, r/e discrimination, negative health care experiences
- **Participant Economic barriers**—poverty, costs of participation, low SES, limited health literacy, transportation, lack of insurance
- **Other**:—eligibility criteria, scheduling conflicts, confidentiality concerns, denial of risks, lack of time, lack of child/eldercare, family obligations, lack of information about study or study benefits
Other Barriers

- **Study Design barriers**: complex forms, procedures, provider time constraints

- **Investigator barriers**: cultural differences between researcher & target population, inadequate pre-study preparation
Strategies to address barriers

- Prior to study: utilize focus groups and key informant interviews to identify & understand potential barriers and seek solutions
- Hire bilingual staff and/or utilize medical interpreters where appropriate
- Ensure translated materials are linguistically and culturally appropriate
- Materials at lowest reading level possible (for all)
Additional Suggestions

- Create FAQ sheet addressing potential concerns to clear up misconceptions
- Be clear on benefits of participation
- Pre-preparation by Investigators to community setting & population
- Commit to CBPR tenants: seek collaboration & advice from trusted community leaders & others in all study aspects
Additional Suggestions

- Consider **funds** for community-based collaborators

- Where possible: **minimize need** for child/elder care by minimizing transportation; funds for above

- Respect: **Follow-up** with telephone call

- Use **multiple R & R strategies** (posters, direct phone calls, key leaders, one on one meetings, events)
Recruitment Materials:

- Be clear that **activity is research**
- Potential **benefits** of participation—not coercive or misleading
- **Compensation**—not overly emphasized, coercive or misleading
- **Free of** deception and exculpatory language
- Font size or other visual effect **not coercive or misleading**
- Language & terminology—**appropriate** for audience

IRB Policy Committee, Ohio State University, Human Research Protection Program Policies and Procedures, 4/28/09
5. Pilot test Recruitment Strategies

- Enlist focus groups & key informants to **get ideas** on effectiveness & appropriateness of specific recruitment strategies for each target

- **Follow-through** when possible with suggestions

- **Monitor** effectiveness of your strategy
Hawai'i Examples

- The Geriatric Care Home Study
- The Ha Kupuna Listening Study
- Hawai'i State Legislature Study
Geriatric Care Home Study

**Goal:** Identify role of ethnicity and culture in care home operator career choice

**Multi-stage recruitment strategy—**What Worked:
- Identified influential legislative leaders & groups
- Shared goal, enlisted advice
- Community letter & follow-through
- Individual meetings if Health literacy was low
- Response Rate: 90%
Ha Kupuna Listening Study

- **Goal:** Identify LTC needs, issues, & service preferences among Native Hawaiian elders & family caregivers.

- **What worked:** Island champion, support & reminders from key NH & other leaders, easily accessible & familiar site.

- **What did not work:** Did not identify “right” leaders, no champion, too “academic” in communication, researchers not well known, site not easily accessible, transportation?
Hawai`i Legislative Study

Goal: Identify state-wide health and LTC needs of elders, families and Service Providers

- Design: Focus group, all major islands, groups separated by elder, family & SP
- Funding: Legislature and Executive Office on Aging
Recruitment:

What Worked: Credible researchers, support of each island’s AAA director & staff, & State EOA Director
- Presentations to Outreach staff on study purpose (get more funds for services!)
- Easily accessible sites for participants
- Flyers (in senior sites): Food & gifts for participants

What Did Not Work: Some caregivers could not attend due to caregiving—we made no arrangements for this, also offered one session on each island for each group—multiple would have increased sample size
Effective Recruitment Strategies for Clinical treatment Trials

- Hire recruitment coordinators if possible
- Use multiple strategies
- Consider recruiting minority health care providers & faculty as collaborators
- Consider using staff as patient educators or counselors

Harvard University, Initiative to Eliminate Cancer Disparities (IECD), 2005. Harvard: MA.
Effective Recruitment Strategies for Prevention Trials

- Work with community (e.g., clinics, providers)
- Consider media promotion in all aspects
- Gain respect & trust of target community, provide outreach services that address needs central or not to the study
Strategic Plan on Reducing Health Disparities NIH Clinical Center

Establish active public information/outreach

1. Increase public awareness of research
2. Eliminate misinformation
3. Foster positive public perceptions
4. Target minority media, newspaper, magazines
Strategic Plan on Reducing Disparities in NIH Clinical Center

Develop Infrastructure and Outreach Activities:

1. **Tailor** R & R process to facilitate minority participation in clinical trials
2. **Maintain/commit** to an ethnically diverse staff
3. **Track** minority accrual & referral rates
4. **Evaluate** effectiveness of minority recruitment strategies
Retention Strategies

- How will you retain participants?
- How will you monitor retention?
Suggestions:

- **Communicate** long-term commitment to study
- Clearly **explain** study requirements
- Be **flexible**
- Send **tokens** of appreciation
- Track participation; follow through ASAP with problems
- Send out newsletters about **progress**
- Provide services (**reciprocity**) 
- Report and **disseminate** results
Some Final Thoughts:

- What can I contribute to my community in a way of knowledge?
- What relationships can I build?
- How can I better prepare myself or my staff to working with my community?
- What can the community teach me about being a better researcher?
Helpful resources

- BRFSS (Behavioral Risk Factor Surveillance Survey)
- NIH resources from all institutes: [http://www.nih.gov](http://www.nih.gov) (overall information)
- NIH Outreach Notebook [http://www4.od.nih.gov/orwh/outreach.pdf](http://www4.od.nih.gov/orwh/outreach.pdf) for the inclusion, recruitment and retention of Women and Minority Subjects in Clinical Research

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