Institute for
Aging Research

Hebrew SeniorLife

Institute for
Aging Research
Hebrew SeniorLife

Successful Recruitment of Older Participants to Clinical Research Studies:

Lessons from the Harvard Cooperative Program on Aging

Marcie Freeman, M.Ed.

Director, Outreach and Recruitment
Harvard Cooperative Program on Aging
Massachusetts Alzheimer's Disease Research Center
Education/Recruitment Core
Chair, Multicultural Coalition on Aging

Affiliated with
Harvard Medical School

That Old Sinking Feeling

Speaker shares successful and innovative strategies

↓

Listener thinks to self: *gasp, we don't do those things!* (unaware, no time/staff/funding)

↓

Where does that leave us?

What Compels Us?

➢ NIH Revitalization Act of 1993 establishing guidelines for inclusion of women and minorities in clinical research, *to ensure that study design support the analysis of potential differences between gender or racial subgroups*

➢ IOM *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, 2002* - health disparities: *differences in the incidence, prevalence, mortality and burden of disease and other adverse health conditions that exist among specific population groups in the U.S.*

Affiliated with
Harvard Medical School

Institute for Aging Research
Hebrew SeniorLife

➢ Population Shift

Nationally:
Total US population in 2000, 30% Minorities
By 2050, Minorities will reach 50%
  and will comprise 35% of the 65+ population

Locally:
 Currently, 7% of elderly are minorities,
but 50.5% of adults under age 65 are minorities
65+ population will increase 46% in next 25 yrs.

Boston is already a "minority majority" city.

Older Adults
our "Special Population"

➢ Underrepresented in clinical research

➢ Growing in numbers

➢ Increasingly diverse (culture/language)

➢ Experiencing conditions associated with aging

IFAR Response

Established in 1991 to: 1) provide well-characterized, representative cohorts of older adults for clinical research studies and 2) disseminate research information to Boston's diverse communities

➢ Funded by multiple sources over time (OAIC, RNH, MADRC)

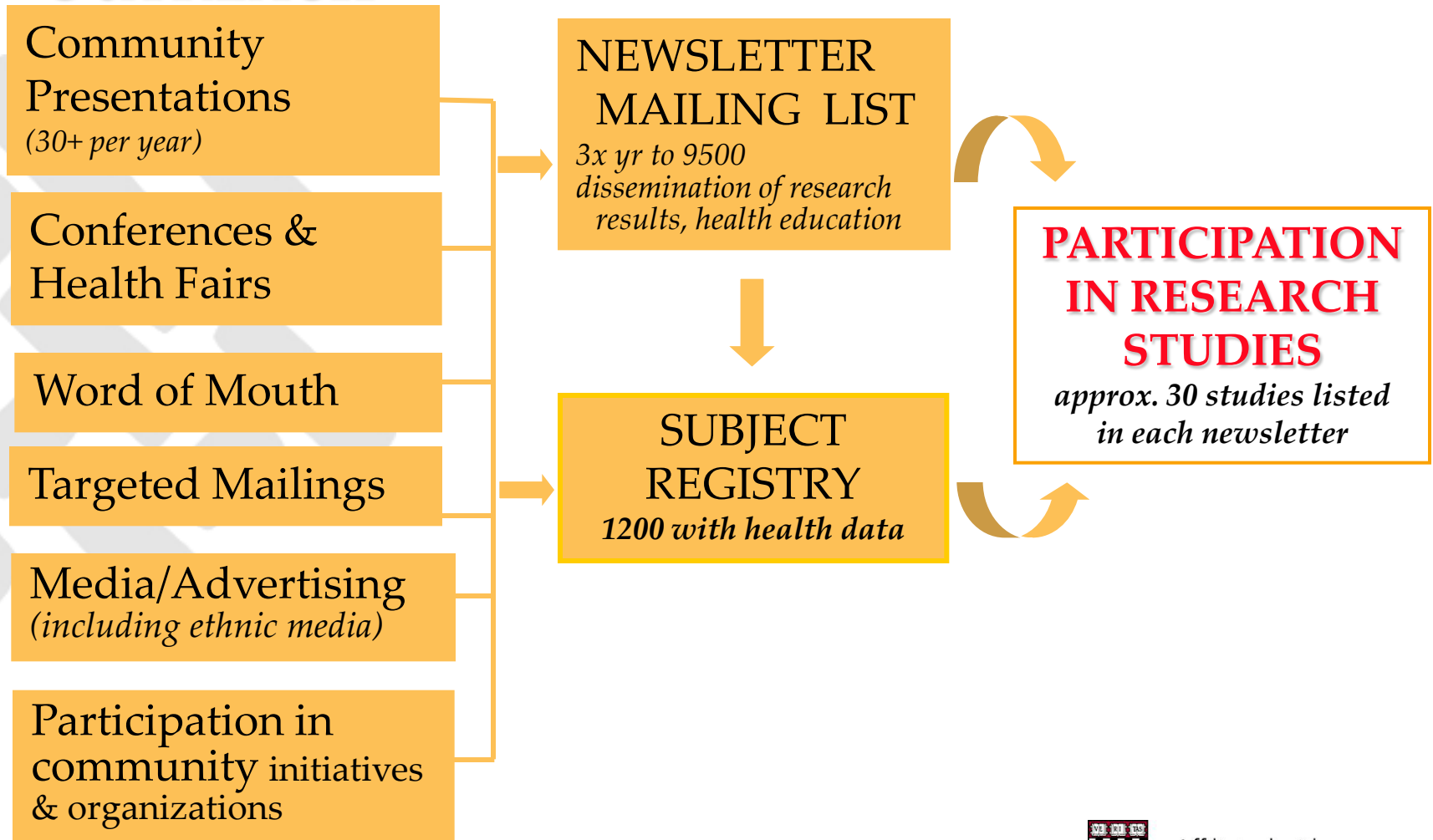*Program name:* **Harvard Cooperative Program on Aging (HCPOA)**

Methods:
➢ Engage in Community Outreach and Education

➢ Build and Maintain a representative Subject Registry of healthy, community-dwelling older adults

➢ Match Older Adults to Research Studies

➢ Disseminate information about research/healthy aging

➢ Participate in Community Initiatives

Affiliated with Harvard Medical School

Recruitment for Multiple Research Studies

Fee-Based Recruitment for Investigators/grants not affiliated with Institute for Aging Research/HSL

➢ HCPOA "Subject Request Forms", IRB approval etc.

➢ HCPOA sends study info to pre-qualified subjects through Registry (based on health criteria), and

➢ Lists study in HCPOA Newsletter

Registry member PHI never provided to PI s, all contact made through mail, if interested in study, they contact research teams directly.

Results: over 350 studies for 40+ research institutions

Affiliated with Harvard Medical School

"Usual" practices inadequate

Existing recruitment methods insufficient to recruit representative cohorts of increasingly diverse communities

➤ Researcher imperative to recruit diverse populations into research studies

➤ Burden of research demands on community in Boston

➤ CBO need to protect vulnerable populations, use available resources to provide services

Community Readiness Limited by:

- Mistrust and/or poor perception of medical & research community, reluctance to engage

- Language: *communication, literacy*

- Cultural factors: *beliefs about health, illness, science, authority/government, immigration/acculturation experiences*

- Environmental: *access/transportation, lost work time, finance/economics, safety, unfamiliar with rsch. institutions*

Affiliated with
Harvard Medical School

Researcher Readiness Limited by:

Failure to Create a Recruitment Plan & Associated Budget Specific to Target Populations

Lack of Attention to Cultural Context in Recruitment Activities /Materials (*resulting in miscommunication or even offense to the target audience*)

Failure to Address Environmental Barriers (*confirming suspicions that researchers don't understand community needs*)

Approaching the Community "after-the-fact" (*confirming belief that researchers are just "using" the community*)

You call this a plan?

204 Boston area researchers were asked:

"Do you have a plan for recruitment of minorities?"

95 said No,   109 said Yes

Of those saying YES, plans were: "actively trying", "none", "will advertise", "will not turn anyone away", "equal opportunity", "mail sent to minorities", "minorities are welcomed", "outreach", "encourage minority participation"

and similarly detailed, well considered plans.

2004 HRCA Survey of Subject Request Forms

Affiliated with
Harvard Medical School

Innovation or Extinction

New practices required: innovative models of communication and partnership based on the principle that direct participation of representatives of target populations in the design and implementation of programs affecting those populations is essential,

Enter the

MULTICULTURAL COALITION ON AGING
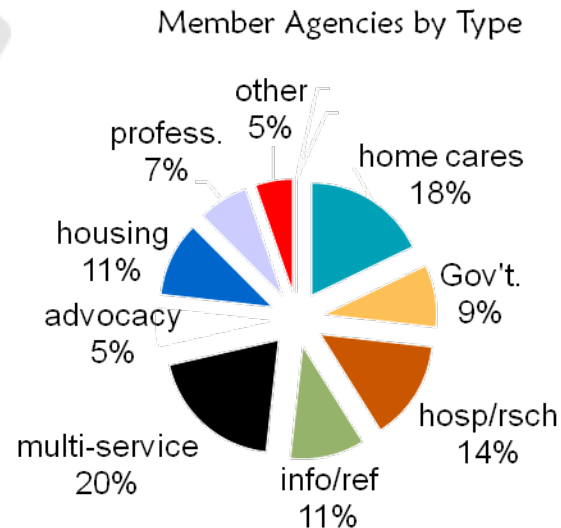
MULTICULTURAL COALITION ON AGING
Improving the delivery of health care & social services to culturally diverse older adults

A city-wide coalition of 65+ agencies and organizations providing health and social services to diverse older adults in Boston and beyond since 1994.

The Coalition creates a network of agencies & links individuals with a common interest in empowerment and capacity building.

➢ *For consumers:* increasing access to culturally/linguistically appropriate information, services

➢ *For agencies:* increasing competence to provide services across cultures and languages

➢ *For researchers:* access to hard to reach communities, increasing diversity of participants, availability of informed partners

Member Agencies by Type

other 5%

profess. 7%

home cares 18%

housing 11%

Gov't. 9%

advocacy 5%

hosp/rsch 14%

multi-service 20%

info/ref 11%

Affiliated with
Harvard Medical School

Coalition Member Benefits

➢ Capacity to respond to increased competition, dwindling resources

➢ Respond to changes in demographics: number of elderly, racial and linguistic diversity

➢ Increase cultural relevance of products or services

➢ Collaborative development of culturally, linguistically appropriate programs, materials

➢ Key to competent service delivery, agency survival

Coalition impact on Research Recruitment

- Increases visibility of the research agenda at monthly meetings and conferences – connects research to every member agency's interest in eliminating disparities in health outcomes of their clients

- Disseminates research information through agency members

- Teaches community agencies the value of partnering with research institutions and how to establish mutual benefit

- Increases cultural competence of research teams by increasing their awareness of cultural, linguistic influences on ability and willingness of agencies and consumers to participate in research

- Provides access to bilingual, bicultural staff to facilitate recruitment and retention

- Creates forum for sharing best practices, efficient use of resources and decreasing burden on minority community

Affiliated with
Harvard Medical School

Special Considerations: *Diverse Communities*

Social/cultural barrier	Difficulty Presented	Strategy
Perception of research or medical community	Prior actual or perceived exploitation by researchers Negative experiences with the medical establishment Reputation of research institution regarding minority communities Fear of side effects or invasive test procedures	Work with community advisory board for guidance on community and culturally specific concerns. Plan for local dissemination of study results, related information of value to the community. Ensure that study staff understands issues and protections in place for the current study
General mistrust	Questions about legitimacy and importance of the study Increasing awareness about scams targeting older adults, making it difficult to discriminate between legitimate opportunities & others	Ask community advisory board, housing, and service agencies to offer assurance about legitimacy of the study. Clearly identify all staff with photo Ids. Provide continuity in research staff/contacts.
Gatekeepers	Family members, caregivers, or service providers may influence participation decision, especially influential when they share language, culture and are relied on for their opinions.	Conduct pre-recruitment community education plan with resident councils, housing staff etc. to address uncertainty. Modify materials to potential participants and family members. Communicate and work with a family member who wants to be involved.

Harvard Medical School

Special Considerations: *Diverse Communities*

Social/cultural Barrier	Difficulty Presented	Strategy
Culture	One approach does not fit all. Meaningful experiences are interpreted within the sphere of one's own culture. Assumptions based on stereo-types or insufficient info will not work.	Build a culturally aware research team, including members of the target community. Be aware of culture and assumptions of research institution and staff. Apply cultural knowledge to recruitment process.
Privacy	Fear that privacy will not be protected Fear loss of services or eviction from housing, immigrants may fear contact with authorities	Train staff in all levels of privacy protection. Listen to and address the specific concerns
Motivation	Potential participants may need help determining reason to participate.	Address motivations such as stipends, health screenings, meal vouchers, newsletters, contribution to future generations, relevance of research topic to participant's ethnic/age group.
Language	Enrolling & testing Limited English Proficiency participants is more complex than providing translations. Communication may be difficult or *unreliable*. Same information, telephone support must be provided to ALL participants in language they understand.	Know the demographics of the study area. *Set parameters on the level of English language proficiency required to qualify subjects*. Use standardized translations of instruments. Employ bilingual staff, use interpreters.

Harvard Medical School

Special Considerations: *Diverse Communities*

Social/cultural Barrier	Difficulty Presented	Strategy
Literacy	Half the adult population is functionally illiterate at the eighth-grade level. Recent immigrants may have low literacy also. Length, complexity of study materials, including consent forms, descriptive materials, testing materials create a barrier	Use "readability" guidelines to achieve a suitable grade level. Provide two versions of the consent form: one a shortened, bulleted summary for easier reference.
Location of testing site	A site outside participants' community may be unfamiliar or intimidating, esp. for those with sensory or motor deficits, or who live in cultural or linguistic enclaves	Consider which research activities could be conducted in familiar community settings. Provide home visits if possible.
Competing responsi-bilities	Participants may have caregiving respon-sibility for spouses, adult children, or grand-children, as well as medical appointments, work, civic, and other commitments.	Provide flexible scheduling opportunities, Assist participants with special circumstances.

Special Considerations: *AGING*

Health Problem	Difficulty Presented	Strategies
Hearing	Difficulty hearing study descriptions, informed consent; making telephone appointments, completing interview assessments	Use handheld hearing augmenters (in-person), telephone amplifiers And written materials Dedicate a phone line with clear message
Vision	Difficulty reading study materials, performing written assessments	Use large, bold fonts Identify staff with large ID badges.
Cognitive slowing	Enrollment, assessment, and other research tasks more difficult, take longer, cause frustration for participant	Encourage & reassure participants during enrollment & data acquisition; allow extra time Send appointment reminders, make reminder phone calls

Affiliated with
Harvard Medical School

Special Considerations: *AGING*

Health Problem	*Difficulty Presented*	*Strategies*
Dementia or Delirium	Difficulty (or inability) understanding study procedures.	Conduct communication, informed consent process through know-ledgeable caregiver; consider formal guardian if required. Consider *assent* from participant (at enrollment & over time) or consent from both (mildly demented) participant and caregivers.
Manual dexterity	Difficulty or inability signing name, completing cognitive screening tests or written portions of protocols	Adapt for verbal response, have someone record responses, if appropriate.
Multiple Comorbidities, frequent hospitalizations	Difficulty keeping scheduled appointments for Initial and follow-up assessments.	Have protocols for managing missed follow-ups and assessments in hospital or postacute facility. Obtain reliable proxy contact with information about participant.

Affiliated with
Harvard Medical School

Special Considerations: *AGING*

Health Problem	Difficulty Presented	Strategies
Easy fatigability, shortness of breath (e.g., chronic obstructive Pulmonary disorder, heart failure, terminal condition)	May be unwilling to enroll, or to continue, because of lengthy surveys and some physical tasks	Provide reassurance and extra time. Separate tasks into smaller section. Build in breaks as needed. Identify, address specific concerns.
Acute illness, severe pain	Frequently unavailable by phone. Difficulty keeping scheduled appointments.	Approach later. Provide materials for review at home. Enlist caregiver or spouse to aid. Separate tasks into smaller sections, allowing for breaks.
Homebound due to chronic conditions or advanced frailty	May be unable/unwilling to visit study site or participate accurately via telephone	Construct assessment protocols to accommodate in-home assessments.
Mobility issues/ Transportation/ Fall risk	Concern about falling, no longer driving, cost of transportation, discomfort with public transportation	If fall-prone subjects must be included, identify and address their concerns. Train RAs to acquire physical assessment data safely without increasing fall risk. PROVIDE or compensate for transportation.

Freeman's First Rule
for Successful Recruitment in Diverse Communities

Relationships between research institutions and the communities in which they reside are necessary for successful collaboration, and require long-term financial and programmatic commitment by the research institution.

Method: Community Advisory Board (or defacto)
Enlist cultural advisors/informants/partners from diverse communities
Invest resources in them, building their capacity to serve their clients

- ❖ Informs research team, recruitment process about community characteristics and needs
- ❖ Opens cross-cultural dialogue
- ❖ Strengthens Center's reputation in community
- ❖ Opens doors for community collaborations
- ❖ Augments recruitment efforts
- ❖ Increases research participation by diverse clients of members agencies

State of the Art

PUBMED search for:

"recruitment methods", "minority recruitment" "participant recruitment strategies" "enrollment of women and minorities", "recruitment of older"

= 1609 citations

The bottom line - there are plenty of resources for anyone wishing to plan effective recruitment of research participants.

Reality Bites

Q: Are recruitment strategies planned in advance?
Are these plans informed by the literature or best practices?

A: Basic description/budget requirements in proposals, not informed by current best practice, not tailored to specific population, often absorb budget cuts

Q: Who do is usually conducting recruitment activities?

A: RAs, recent grads, no recruitment training or support, short-term positions, may have little understanding of the experience of an older adults

Q: Is there support for the necessary long-term community relationships from funders/institutions?

Q: Do institutions/research staff understand that awareness of cultural/linguistic appropriateness is critical to success?

What is the *cost* of continuing to practice "uninformed" research recruitment?

➤ Inadequate representation of diverse population in research ⟶ diminished generalization of research results

➤ Continued legacy of poor relationship with diverse communities, or worse, new wounds ⟶ further distance between research institutions and population

➤ Recruitment and assessment of English-speaking only population ⟶ underrepresentation of people with Limited English Proficiency

➤ *and more …?*

Acknowledgements

Lewis A Lipsitz, MD

Director, Senior Scientist, Institute for Aging Research

Irving and Edyth S. Usen and Family Chair in Medical Research

Chief, Division of Gerontology at Beth Israel Deaconess Medical Center

SOURCES

Contemp Clin Trials. 2008 Nov;29(6):847-61. Epub 2008 Jul 31. Recruitment of minority and under-served populations in the United States: the Centers for Population Health and Health Disparities experience.

Mody L, Miller DK, McGloin JM, Freeman M, Marcantonio ER, Magaziner J, Studenski S. Recruitment and Retention of Older Adults in Aging Research Journal of the American Geriatrics Society 56:2340-2348, 2008.
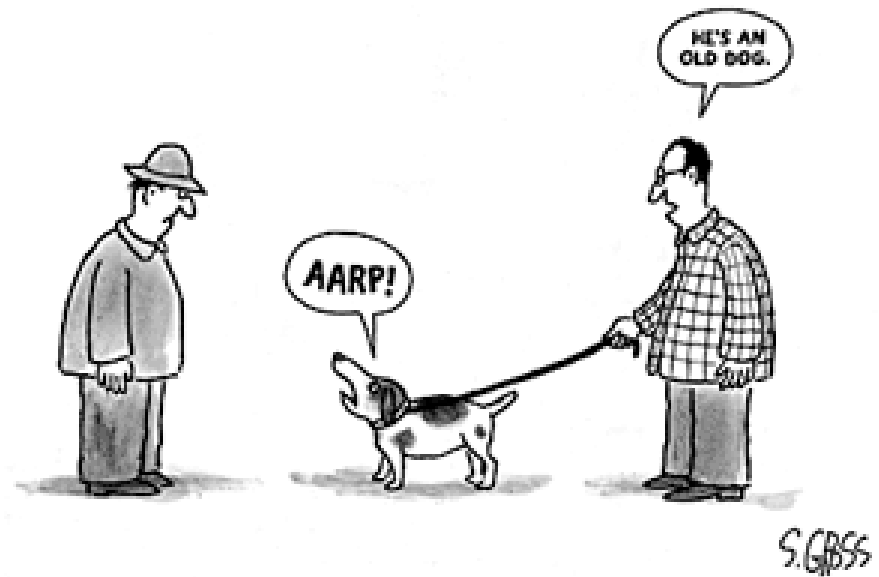
Samelson EJ, Kelsey JL, Kiel DP, Roman AM, Cupples LA, Lipsitz LA, Freeman MB, Jones RN, Hannan MT, Leveille SG, Gagnon MM, Lipsitz LA. Issues in Conducting Epidemiologic Research in Elders: Lessons from the MOBILIZE Boston Study. Am J Epidemiol. 2008 Dec 15; 168(12): 1444-51

US Census Bureau/American Factifinder

Affiliated with
Harvard Medical School

THANK YOU!

Contact Information:
Marcie Freeman, MEd
freeman@hrca.harvard.edu
Tel: 617.363.8654