Publications on Using Health Registries to Recruit Diverse Older Adults

One specific type of innovative recruitment strategy is the creation and use of health registries. CADC faculty (Drs. Celia Kaplan, Tung Nguyen, and Leah Karliner) reviewed six publications and report systematically some methodological aspects of developing and implementing health registries targeting older adults. Two topics are covered:

- Building a health registry for recruitment of diverse older adults (three studies)
- Assessing different methods of recruitment to join the health registry (three studies)

Topic: Building a Health Registry for Older Adults

Chadiha LA, Washington OG, Lichtenberg PA, Green CR, Daniels KL, Jackson JS. Building a registry of research volunteers among older urban African Americans: Recruitment processes and outcomes from a community-based partnership. The Gerontologist. 2011;51(suppl_1):S106-S115.

Summary: This study retrospectively described recruitment methods and outcomes in increasing the number of research volunteer registry participants among African Americans aged 60 and older living in inner-city Detroit. Researchers assessed the increase in participant enrollment over 7 years: from 102 to 1,273 registry participants. Both direct and indirect recruitment methods were utilized—mainly asking residents in-person to complete an evaluation survey, then following up over the phone to enroll them in the registry. The registry has been used to recruit participants in 9 studies.

Study Purpose:	**Type of Study:**	**Population:**	**Recruitment Methods:**	**Results:**
Build a volunteer registry to increase research participation of older urban African Americans over 7 years Compare registry enrollee gender and age to that of a sample from a population-based random survey	Retrospective case design Used logic model to evaluate program activities	Older African American residents of inner-city Detroit, >60 years In 2009 registry, 99.7% African American, 92.5% women, mean age 74.9 years 2009: 1,273 registry volunteers	Direct methods: Done via a community outreach partnership (Healthier Black Elders Center)—including Community Advisory Board (CAB), older adult volunteers (10-12 people), service agents, financial sponsors, and community outreach specialist. Through health educational community outreach (year-round educational events and annual health reception): Community outreach staff and CAB members asked residents to fill out a brief evaluation survey and provide contact information. Then conducted follow-up telephone interview to obtain consent to enroll in registry Indirect methods: Local radio and TV announcements, annual newsletter from educational outreach program, and referrals from other volunteers	After 7 years of direct and indirect recruiting, increased research volunteer registry from 102 to 1,273 participants Out of 1,100 participants in 2009 annual health reception, 541 completed a self-administered evaluation questionnaire 2004: 82% increase in registry enrollment 2005: 53% increase 2006: 15% increase 2007: 143% increase 2008: 14% increase 2009: 40% increase Registry has been used in 9 studies so far

Topic: Building a Health Registry for Older Adults

Dowling NM, Olson N, Mish T, Kaprakattu P, Gleason C. A model for the design and implementation of a participant recruitment registry for clinical studies of older adults. Clinical Trials. 2012;9(2):204-214.

Summary: As part of the Wisconsin Alzheimer's Disease Research Center, this study evaluated and improved its web-based registry, which recruited older adults. Researchers sought to improve staff-registrant communication, minimize the information needed to recruit participants, and increase enrollment among rural populations, minorities, and individuals with underlying cognitive disorders. This study focused on the electronic management of the registry rather than recruitment strategies. Direct recruitment methods included community events, promotional activities, advocacy referrals, and clinical referrals. Indirect methods included recruitment brochures, newspaper/medical bulletins, and announcements.

Study Purpose:	**Population:**	**Recruitment Methods:**	**Results:**
Describe the web-based registry design model, which focused on recruitment of older adults with specific cognitive and medical characteristics for clinical studies. Concept: A multidisciplinary team using an iterative design process to develop a new programmatic tool with two goals: (1) Improve communication between staff and potential registrants and (2) record minimal information needed to identify potential participants. Part of the Wisconsin Alzheimer's Disease Research Center (ADRC).	Initially drew from an existing ADRC registry database of over 2000 registrants collected over 3 years (already consented to translational research in dementia). Target population: Special consideration to include individuals from rural areas and racial/ethnic minorities. Focus on participants with memory impairments due to underlying cognitive disorders. But also included cognitively healthy individuals. ADRC is also focused on translational research in dementia and further studies in preclinical diagnosis, early diagnosis, and progression of Alzheimer's disease.	From sources of referral: the Wisconsin ADRC outreach program made registry brochures and organized community events, conferences, and promotional events. Newspaper announcements and medical bulletins. Advocacy and clinical referrals. Then outreach staff would call potential participants. They recorded the following de-identified demographic general medical information: age, gender, ethnicity-race, source of referral, diagnosis of memory disorder, parental history of memory disorder, intake of medications for memory disorder, pacemaker, spinal taps/MRI scans, zip code. If potential participants did not consent to screen or did not meet participation criteria, their de-identified information is kept. Otherwise, staff would proceed with the full ADRC registry screening script and, if eligible, register the participants and collect their preferences for contact. Documented verbal consent. The electronic contact record monitors registrant characteristics and all communication with staff. Compiled functional specifications of web-based application for registry design in Table 1.	Advantages to Wisconsin ADRC registry system: Recruitment is managed electronically and any staff member can see potential registrant's contact history. Preferred method of communication is recorded and efficiency can be evaluated. Anonymous demographic information enhances registry population diversity. The registry was "released" 3 times over 5 weeks, with improvements made before each release. Total of 580 person-hours spent. All study coordinators met quarterly to review registry use and standardize methods of documenting interactions with registrants. Key challenge: Initial financial investment in infrastructure and appropriate personnel to develop registry.

Topic: Building a Health Registry for Older Adults

Grill JD, Hoang D, Gillen DL, et al. Constructing a Local Potential Participant Registry to Improve Alzheimer's Disease Clinical Research Recruitment. Journal of Alzheimer's disease : JAD. 2018;63(3):1055-1063.

Summary: This study described the effectiveness of the online Consent-Contact (C2C) registry, which targeted cognitively normal older adults. Most registry participants were female and non-Latino Caucasian. Over one year, 1,184 individuals were contacted and 592 (50%) enrolled in the registry. The most successful recruitment methods were newspaper ads (35% of registry enrollment) and educational presentations (20%), in which participants were enrolled using iPads. Other methods included television, radio, walks/fairs, referrals, email lists, and internet postings. The registry has been used to recruit participants in at least 9 studies.

Study Purpose:	**Population:**	**Recruitment Methods:**	**Results:**
Report on development and effectiveness of on online local participant registry targeting older adults. Part of the Consent-to-Contact Registry (C2C) at the University of California, Irvine--Everything is done electronically. Via REDCap.	Targeted cognitively normal older adults that meet specific genetic or biomarker criteria. For preclinical Alzheimer's Disease Trial. Registrant characteristics: Mean age = 63 66% female 88.2% Caucasian 6.3% Latino 6.9% Asian American	Online enrollment and data collection. 1. Earned media (help from *pro bono* PR firm)—53 publicity stories -**Newspaper (35%)** -Television (1%) -Radio (1%) 2. Community outreach -**Public education (20%)**—121 attendees on average -Walks/fairs (2%)—392 attendees on average 3. Referrals -Friends (18%) -Research participants (2%) -UCI MIND (2%) -Partner organizations (2%) -Physician (1%) -Alzheimer's Association TrialMatch (<1%) 4. Email -UCI MIND list (7%) -UCI campus email (1%) 5. Internet -Search (4%) -Social media (3%) -News (<1%) -Blog (<1%) 6. Other/Unknown (5%)	In first year: Reached out to 1,184 individuals on distribution list via email. 957 individuals submitted their emails (not enrolled) Of which, 592 reported their demographic, family history, and medical data (enrolled) 76/298 contacted registrants enrolled in studies.

Topic: Assessment of Different Registry Recruitment Strategies

Green MA, Kim MM, Barber S, et al. Connecting communities to health research: development of the Project CONNECT minority research registry. Contemporary clinical trials. 2013;35(1):1-7.

Summary: As part of Project CONNECT in North Carolina, this study assessed recruitment methods targeting African American individuals. Of the 608 registry enrollees recruited over 4 years, most were African American and female. The most effective recruitment strategies among older adults were public databases and community outreach due to direct contact. While community outreach was the most expensive and time-consuming, it resulted in the most enrollment. The least effective methods were recruiting from existing studies and radio announcements.

Study Purpose:	**Population:**	**Recruitment Methods:**	**Results:**
Assess both direct and indirect recruitment methods targeting African-American community members. Part of Project CONNECT, which works with the local African American community to address disparities research. By UNC Chapel Hill.	Inclusion criteria: self-identifying African Americans age 18 years or older. 608 individuals, mostly African American, female, in good health.	Direct methods: 1. Existing studies (n=14)-reached out to 500 individuals from cancer study. Enrolled them via returned postcards and up to six follow-up phone calls with verbal consent. 2. Public databases (n= 63)-A commercial sampling company (Shaw CSR) randomly selected individuals in 4 NC counties and conducted telephone recruitment. Then project staff followed-up with the enrollees. 3. Community outreach (n= 268)-in 22 urban and rural communities. Staff set up community presentations, orientation sessions, and health fairs/conferences hosted at Black churches and community organizations. At end of presentations, staff invited attendees to enroll in registry and informed consent obtained. Also met with church leaders first to discuss project. Indirect methods: 1. Radio (n= 7)-Targeted 3 regional radio stations in a six county metro-area with 1.3 million people. 2 announcements for 6 weeks. 2. Internet (n= 75)-Individuals can self-enroll in the registry if they received print material, emails, or self-guided searches. 3. Email (n= 182)- Mass email to university students, faculty, and staff. New registry members received nominal incentives of pens, cups, magnets embossed with the project CONNECT logo. All registry members received Project CONNECT newsletter to ensure all members are aware about research updates and opportunities. 14 staff members.	Total of 608 registry participants between 11/2004 and 10/2008. Email and internet methods appealed most to younger enrollees. Public databases and existing studies were most effective for older enrollees. Older enrollees most preferred face-to-face contact. Community outreach appealed to both groups equally. Existing studies and radio resulted in the fewest registry enrollees. Community outreach has the most time-consuming and required more staff time, but resulted in the most enrollment. Outreach settings: churches, health fairs/screening events at local community centers, health focused conferences, African American sorority/fraternity events, large African American events. Outreach events: 37% presentations/conferences, 34% health fairs, 15% outreach sessions, 13% vendor exhibits, 1% print media.

Topic: Assessment of Different Registry Recruitment Strategies

Johnson KJ, Mueller NL, Williams K, Gutmann DH. Evaluation of participant recruitment methods to a rare disease online registry. American journal of medical genetics Part A. 2014;164(7):1686-1694.

Summary: As part of the NF1 Patient Registry Initiative, this study reviewed the effectiveness of four direct recruiting methods used in an online patient registry. 880 individuals were recruiting over one year from across the United States and other countries. The target population was English-speaking self-identified NF1 individuals. The most effective method was paid Facebook and Google advertising (62.5%). The least effective methods were patient advocacy groups and indirect recruitment methods.

Study Purpose:	**Population:**	**Recruitment Methods:**	**Results:**
Describe effectiveness of four recruitment methods used in online patient registry targeting "self-identified neurofibromatosis type I (NF1)". Part of NF1 Patient Registry Initiative (NPRI) by Washington University in St. Louis	Recruited from the US, Puerto Rico, and 39 other countries (especially Australia)—targeted English-speakers Targeted NF1 individuals (rare disease). Mean age: 29 Mostly white, female. 10% Hispanic. 32.4% over age 40. 73.1% from the US.	Direct Recruitment Methods: 1. Facebook and Google advertising • paid, through Facebook Ad and Google Adwords campaigns; Paid on cost-per-click basis w/ budget: $12/day for Google and $10/day for Facebook 2. Government and academic websites • study listed on clinicaltrials.gov and university sites 3. Patient advocacy groups • identified 43 groups—asked them to advertise the registry and send emails to members 4. Healthcare providers • sent study invitation letters to potential patients at Washington University • sent information cards to be distributed at several NF centers. Indirect Methods: Other, word of mouth, NF conference, Inspire, referred by participant through an email, Wikipedia, twitter, etc.	Asked participants about recruitment method via online questionnaire. Over 1 year (1/1/2012-12/31/2012), 880 individuals in registry. 89% of participants heard about registry through direct recruitment methods. 550/880 recruited from Facebook (72%) and Google (28%) 74/880 from healthcare providers 71/880 from government and academic websites Most effective: Online advertising (Facebook) Least effective: Direct mailed letter recruitment, government/academic websites, advocacy groups

Topic: Assessment of Different Registry Recruitment Strategies

Ramirez AG, Miller AR, Gallion K, De Majors SSM, Chalela P, Arámburo SG. Testing three different cancer genetics registry recruitment methods with Hispanic cancer patients and their family members previously registered in local cancer registries in Texas. Public Health Genomics. 2008;11(4):215-223.

Summary: This study randomized 444 Hispanic individuals from South Texas into one of three experimental recruitment method conditions: Standard direct-mailed procedures (X1), X1 + culturally tailored materials (X2), and X2 + interpersonal phone contact (X3). Over 5 months, a total of 154 individuals joined the registry and X3 was found to have the highest recruitment. Thus, interpersonal communication via telephone follow-up was found to be effective. Since X1 and X2 had similar recruitment rates, culturally tailored materials may not have much effect.

Study Purpose:	**Population:**	**Recruitment Methods:**	**Results:**
Prospective study to investigate which recruitment method increases Hispanic enrollment to the Cancer Genetics Network national registry.	Hispanic men and women in South Texas (San Antonio area) previously registered in cancer registries (4 different ones). Included English and Spanish-speaking individuals over age 18. Most had personal and/or family history of cancer. Mainly: Male (59.7%) Mean age: 60.6 White (77.1%) Mexican American (53.8%)	444 individuals randomly assigned to one of three experimental conditions: 1. Standard direct-mailed procedures (X1) • study cover letter, consent form, 2 questionnaires 2. X1 + culturally tailored materials (X2) • *Buena Vida* magazine and questionnaire 3. X2 + interpersonal phone contact (X3) • Telephone follow-up—described registry and offered assistance in completing the forms	Over 5 months, a total of 154/444 individuals joined registry. X3 had greatest accrual (43.2%) v. X1 (30.9%) v. X2 (29.9%). Interpersonal communication (telephone follow-up) was effective. Culturally tailored materials (*Buena Vida* magazine) appeared to have no effect.