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Recruiting the Oldest-old for Clinical Research

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The oldest-old (defined as people age 90 and older) are the fastest growing segment of the population, are at increased risk for dementia, and are distinct from older adults below the age of 90 with respect to clinical and pathologic characteristics.¹ Therefore to inform clinical care reflective of societal demographics it is important to include the oldest-old in research. Yet, this group is consistently underrepresented in research² and little guidance is available to instruct recruitment.

Initiated in January 2003, *The 90+ Study* is a longitudinal study of aging and dementia in the oldest-old. It includes comprehensive semiannual neurological and neuropsychological examinations, as well as blood draws, brain imaging, and neuropathologic examination.¹ *The 90+ Study* originally enrolled oldest-old participants from the Leisure World cohort study (LWCS).¹ LWCS is a health survey study of the residents of the Leisure World (now known as Laguna Woods Village), a large retirement community in Orange County, California. Over time open recruitment beyond the LWCS was initiated due to natural dwindling of the cohort. The aim of this brief report is to describe outcomes and costs of the recruitment strategies used in this open recruitment.

METHODS

Participants

Inclusion criteria for newly recruited participants are: age 90 or older, residing within an hour drive of the study location, no or mild dementia, and no contraindications to brain imaging. Participants must be willing to undergo semiannual neurocognitive evaluations and consider brain donation.

Recruitment Strategies and Activities

We report recruitment performed between January 2014 and April 2017. Recruitment activities were categorized into 4 strategies: community outreach, earned media, direct mailings, and referrals.

(1) Community outreach

(a) During the recruitment period the study team delivered 46 community presentations on longevity and cognitive health highlighting findings from *The 90+ Study* (10 to 22 presentations per year), open to the general public. Four presentations were given in

2 retirement communities near the study location, others at various community organizations in the area. At each presentation, recruitment brochures were distributed enabling attendees to contact the study team if interested in enrolling.

(b) The study team organized 1 recruitment event in the Laguna Woods Village retirement community. Invitations were sent to 1733 individuals age 90 and older living in Laguna Woods Village and 2 neighboring zip codes. Addresses were rented from a contracted mailing house. Oldest-old individuals were invited to learn about the study and consider participation. The event, held in September of 2016, featured study investigators, who presented the study and answered questions. Sixteen current study participants and relatives shared their experiences. In total, 54 potentially eligible individuals (3% of those who received invitations) attended the event. Attendees interested in joining the study were given information packets including consent forms and other study materials.

(c) Study personnel distributed 25 to 50 brochures to each of 10 local retirement communities and senior centers.

(2) Earned media. The study was featured in the media 9 times during the reporting period. We categorized media as (a) national, including Columbia Broadcasting System 60 minutes (aired twice), The Los Angeles Times, and a web podcast, or (b) local, including television, radio, and newspaper. Local media coverage included television and newspaper outlets operated by Laguna Woods Village for its residents. In most cases, coverage was initiated by the media outlet following public presentations or press releases of research publications. An exception was coverage by the Laguna Woods Village outlets, which was initiated by the study team.

(3) Direct mailings. Three direct mailings, separate from mailed invitations to the recruitment event, were performed through a contracted mailing house. Mailings were sent to 16 different zip codes within an hour drive of the study location. A first mailing, in August 2015, was sent to the households of 389 individuals age 96 and older. Subsequent mailings targeting those 90 to 95 years old were sent in December 2016 to 2250 households and in March 2017 to 2350 households. Mailed materials included a study brochure with a postage-paid contact information card.

(4) Referrals. Active study participants and collaborating investigators of the University of California, Irvine Alzheimer's Disease Research Center and Willard Body Program referred 90+ individuals to the study.

Data Collection and Analysis

Recruitment sources were captured through participant self-report at enrollment. To estimate the total cost for each recruitment activity, we summed personnel and material expenses. The cost of personnel time was calculated as estimated staff or faculty time performing target activities (delivering presentations, being interviewed for a show,

answering reporters' questions) multiplied by standard university hourly rates (\$128 for faculty and \$47 for staff, including benefits). Staff time organizing recruitment activities was not included in personnel cost. Material costs were actual dollar amounts for printing, postage, food and beverages, and venue rental. Earned media appearances were free of charge; the only cost was personnel time. Average cost per recruited participant was calculated by dividing total cost of recruitment activity by the number of participants recruited through that activity.

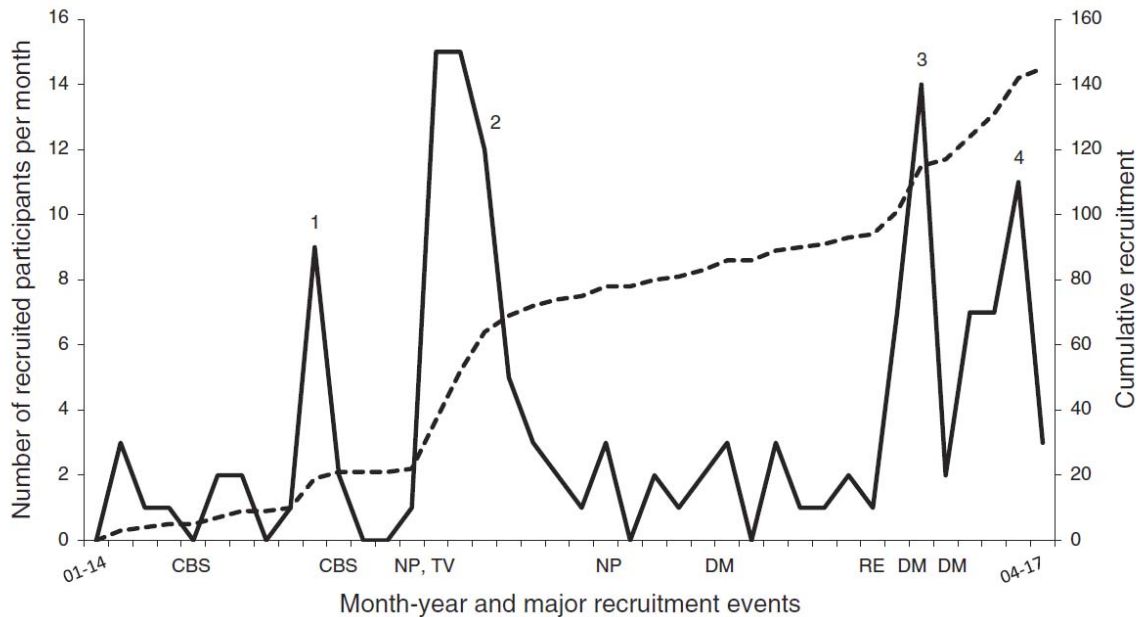


FIGURE 1. Number of recruited participants by month (solid line) and cumulatively (dotted line). Letters indicate timing of major recruitment activities: CBS—CBS 60 minutes (aired twice), NP—retirement community paper (2 publications), TV—retirement community TV, DM (3 mailings), RE. Between January 2014 and peak 1: 6 presentations, 1 earned media (7 activities total). Between peaks 1 and 2: 16 presentations, 4 earned media (20 activities total). Between peaks 2 and 3: 19 presentations, 1 RE, 1 mailing, 4 earned media (25 activities total). Between peaks 3 and 4: 2 presentations, 2 mailings, 2 earned media (6 activities total). CBS indicates Columbia Broadcasting System; DM, direct mailing; NP, newspaper; RE, recruitment event; TV, television.

RESULTS

A total of 145 new participants were enrolled over 40 months (mean, 3.6 participants/month; range, 0 to 15) (Fig. 1). Mean age of the enrolled participants was 93.1 ± 2.9 years (range, 90 to 110 y). Most participants were female (59.2%) and white (96%). Three percent were Asian and 1.5% were Hispanic/Latino. Most of the participants (53%) had completed college, 31% had attained a postbaccalaureate education, and 16% had not attended college.

Data on recruitment source were available for 87% of new enrollees; 2 participants (1.4%) reported >1 source. These individuals were categorized based on the recruitment activity that immediately preceded their enrollment.

Each strategy resulted in recruitment (Table 1). Among the 4 recruitment strategies community outreach produced the highest yield (49 participants, 33.8%) followed by earned media (32, 22.1%) and direct mailings (24, 16.6%). Among specific recruitment activities, community presentations (24, 16.6%), mailings (24, 16.6%), and local earned media (24, 16.6%) had highest yields. Among those recruited through earned local media, each participant reported a local retirement community newspaper as the source of recruitment. Similarly, among those recruited through earned national media, only 1 outlet (CBS 60 minutes) was reported as a source. The direct mailing to the older age group (96+) produced only 1 enrollee (0.2% of households receiving the mailings), subsequent mailings to younger participants yielded 23 enrollments (0.5% of households).

The total estimated cost of this recruitment campaign was \$25,070; the mean cost per enrollee was \$173 (Table 1). Among strategies associated with cost, earned media (\$132) was most cost-effective; community outreach was least cost-effective (\$261). Local earned media (\$31) and distributing recruitment brochures at senior organizations (\$147) were the most cost-effective recruitment activities; national earned media had highest cost per participant (\$480).

TABLE 1. Number Recruited and Cost-Effectiveness by Recruitment Strategies and Activities

Recruitment Strategies and Activities	No. Events	Participants Enrolled [n (%)]	Total Cost (USD)	Cost Per Participant (USD)
Community outreach		49 (33.8)	14,786	261
Presentations	46	24 (16.6)	7988	333
Recruitment event	1	20 (13.8)	6063	303
Brochures at organizations	10	5 (3.4)	735	147
Earned media		31 (21.4)	4093	132
Local media	6	24 (16.6)	734	31
National media	8	7 (4.8)	3359	480
Direct mailing of recruitment brochures	3	24 (16.6)	6191	258
Referrals	—	23 (15.8)	—	—
By <i>The 90+ Study</i> participant/staff	—	17 (11.7)	—	—
Clinical referrals	3	5 (3.4)	—	—
<i>The 90+ Study</i> website	—	1 (0.7)	—	—
Unknown	—	18 (12.4)	—	—
Total	—	145 (100)	25,070	173

DISCUSSION

This report shows the feasibility of recruiting individuals age 90 and older into longitudinal clinical research and provides preliminary guidance related to the effectiveness of recruitment strategies. The recruited sample is representative of the US oldest-old with respect to sex but is more educated,³ much like other research in this age group.⁴ The ethnic composition resembles 2014 census projection for the oldest-old in Orange County, California (74%),⁵ though the percentage of whites may be higher due to the ethnic composition of the specific recruitment areas and other challenges related to underrepresented ethnic groups.⁶

Some recruitment strategies were more effective than others. Consistent with survey research in older adults,⁷ community outreach produced the highest number of new enrollees, but at the greatest cost. Recruitment activities with age-appropriate individuals yielded the most enrollees. Thus, a single targeted recruitment event resulted in nearly as many participants as did 46 general public education presentations, and at a lower cost.

After community outreach, earned media produced the most enrollments and did so at lower cost. Local media had greater yield than national media and were associated with less personnel time. National media, however, may have allowed for widespread dissemination of information and initiated trust building for the study, as 6.9% of new enrollees indicated that they first learned about the study through national media but enrolled after a subsequent local recruitment activity (mailing, retirement community newspaper, or invited presentation). This “two-hit” model of recruitment⁸ may be critical to establishing trust and overcoming skepticism, which may be key to successful recruitment of this population.⁹ Perhaps supporting this notion and in contrast to some experiences recruiting to Alzheimer disease prevention clinical trials,¹⁰ direct mailings were not a cost-effective recruitment strategy when targeting the oldest-old. Direct mail was least effective with those age 96 and older.

Several limitations should be noted. This was not a planned study of recruitment; recruitment activities were not balanced for number, cost, or time. *The 90+ Study* is well-established, highly recognizable, and has the opportunity to recruit from nearby retirement communities with large 90+ populations, which may limit the generalizability of our findings. Twelve percent of enrollees did not remember the recruitment source. There was no way for the study team to assess the validity of participant reports. Nevertheless, this report provides guidance for investigators considering recruitment of 90+ individuals to aging research. Targeted community outreach yielded the most new participants but a comprehensive and multifaceted marketing and recruitment plan may be essential to maximizing enrollment of the oldest-old in clinical research.

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