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## Direct mail recruitment to a potential participant registry

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## INTRODUCTION

The use of participant recruitment registries as a tool to accelerate enrollment in Alzheimer's disease (AD) research has increased, especially after registries were highlighted during the 2012 G8 meeting in London.<sup>1</sup> Recruitment registries are large repositories of individuals who have indicated interest and given permission to be contacted about studies for which they may be eligible. As was outlined in the recent National Strategy for AD Research Recruitment,<sup>2</sup> there is need for a scientific approach to develop improved methods of clinical research recruitment, including identifying optimal registry designs and methods. Previously, AD clinical trials have used mailed postcard campaigns to facilitate broad reach to older populations potentially eligible for prevention trials. In this study, we explored whether postcards could be an effective strategy for recruiting to an online participant recruitment registry. Using a controlled design, we assessed whether three postcard taglines differed in effectiveness for eliciting local community members to enroll.

## METHODS

### Study design

The University of California, Irvine, Institute for Memory Impairments and Neurological Disorders (UCI MIND) and Institute for Clinical Translational Science (UCI ICTS) launched the online UCI Consent-to-Contact (C2C) Registry in August of 2016. The purpose of the C2C is to enhance the efficiency of recruitment to clinical research at UCI, including AD prevention clinical trials.<sup>3</sup> To increase enrollment in the C2C, we mailed recruitment postcards to 100,000 Orange County residents aged 50 years and older from June 18, 2018 to June 28, 2018. A mailing list was rented from a local mailing and

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fulfillment company that has access to comprehensive consumer data on approximately 250 million US consumers via the Acxiom Consumer data file.

Postcards with three unique taglines were sent: “You may be eligible for Alzheimer’s prevention studies at UCI!”, “You may be eligible for research studies on brain health at UCI!”, and “You may be eligible for research studies at UCI!” (Figure 1). Taglines were selected for alignment with the C2C Registry mission and to parallel large successful national recruitment registries (e.g., Alzheimer’s Prevention Registry, Brain Health Registry, and ResearchMatch).<sup>1</sup> Given the emphasis of C2C on recruiting to AD research, more postcards (n=60,000) with the AD prevention tagline were sent than for either alternative tagline (n=20,000 each). The postcards listed unique registry website addresses ([ad.c2c.uci.edu](http://ad.c2c.uci.edu); [brain.c2c.uci.edu](http://brain.c2c.uci.edu); [research.c2c.uci.edu](http://research.c2c.uci.edu)) as a method of tracking enrollment. To assess whether including a telephone option affected the response rate, a subset of 5,000 postcards for each tagline included a telephone number in addition to the registry website address, but our primary analysis focused on groups based solely on postcard tagline. We used WordPress, an open source content management system to create registry website landing pages for each tagline. Postcards described risks, data security protections, lack of cost, and the voluntary nature of the C2C using identical language, and were approved by the UC Irvine Institutional Review Board (IRB). There was no compensation offered for enrolling in the registry. The landing pages instantaneously redirected users to the primary registry enrollment page, ensuring that the experience of users was identical for each randomized group. The domains were hosted on separate virtual machine instances running Linux Debian 9 “Stretch” with MariaDB 5.5 database.

### Assessment of registrant characteristics

Enrollees in the C2C Registry provided demographic information including age, sex, race/ethnicity, and years of education. Self-reported medical information included current medical diagnoses, the number of current prescription medications, and family history of selected chronic diseases such as cancer, cardiovascular disease, diabetes, and AD. We ascertained “willingness to be contacted for studies” using nine questions that inquired about being contacted for studies involving modification of diet/physical activity, cognitive testing, blood draws, Magnetic Resonance Imaging (MRI), Positron Emission Tomography (PET) imaging, approved and investigational medications, lumbar puncture, and autopsy. Research attitudes were assessed using the 7-item Research Attitudes Questionnaire (RAQ) with 5-point Likert-type responses.<sup>4</sup> Subjective cognitive performance was assessed using the Cognitive Function Inventory (CFI).<sup>5</sup>

### Statistical analysis

We used chi-square ( $X^2$ ) tests for the primary comparison of the probability of enrollment across the three postcard groups during the first five months of the campaign. Secondary analyses considered whether the addition of a phone number impacted the probability of enrollment. In exploratory analyses we compared the distributions of responder characteristics across postcard groups using  $X^2$  tests for categorical variables and analysis of variance (ANOVA) for continuous variables. Analyses were performed using SAS version 9.4 (SAS Institute Inc., Cary, NC). All tests were two-sided and we employed a level of

significance of  $\alpha=0.05$ . No adjustment for multiple comparisons was made in the exploratory analyses.

## RESULTS

The postcard campaign recruited 273 new C2C enrollees during the first five months, an overall response rate of 0.27%. The response rate did not differ by postcard tagline (AD=0.27%; brain health=0.27%, general research=0.28%;  $p=0.97$ ). There were no differences observed in response rates for postcards including a telephone number (data not shown). Table 1 further describes the distributions of responder characteristics by postcard type. Participants were mostly female (60%), of non-Hispanic white race (77%), and highly educated (73% with college education or higher). The sociodemographic and health characteristics of responders were quite similar for the three postcard groups. Except for studies involving lumbar puncture, greater than 75% of enrollees reported a willingness to be contacted for studies involving various intervention types and procedures. We did observe differences in the proportion of enrollees who were willing to be contacted for studies that involved approved and investigational medications, modification of diet/physical activity, lumbar puncture, and autopsy, based on postcard tagline; however, no particular discernable pattern emerged.

## DISCUSSION

In this study, we mailed postcards to 100,000 local older adults in an effort to recruit to a participant registry. Only 273 people (0.27%) enrolled in the registry as a result of the campaign. Compared to previous recruitment efforts through mailed postcards, this response rate was lower than expected. For example, to recruit to the Ginkgo Evaluation of Memory (GEM) dementia prevention clinical trial, Fitzpatrick and colleagues sent direct mail invitations to 243,000 older individuals and more than 1% were randomized in the trial.<sup>6</sup> An important distinction between the current results and those in the GEM study, however, is that substantial telephone follow-up was implemented to recruit individuals potentially eligible for GEM, whereas no follow-up either by mail or by telephone was performed in this study. In addition to the lack of follow-up, the observed low rate of enrollment might also be attributed to the requirement that older adults use the printed postcards to instruct accessing a website to enroll. Older adults are increasingly Internet savvy,<sup>7</sup> however, and the C2C was designed specifically for use with smartphones and tablet devices, which may be more prominent among older people. Furthermore, we observed no increase in response rates for recipients who received postcards with telephone numbers. Notably, alternate technology, such as quick response (QR) codes, may have facilitated transitions from postcards to web enrollment but were not utilized in the current study.

Based on these results, direct mail may not be the most cost-effective approach to recruit to online registries. The cost of the postcard mailing was approximately \$20,000, which included renting the mailing list, printing the six versions of postcards, randomly assigning addresses of residents 50 years old and over, and postage. Based on the number of responders, this equates to more than \$73 per person enrolled. Although this number is lower than other cost-per-subject estimates,<sup>8</sup> it is important to note that the purpose of

registries is to enroll very large populations, since enrollment in a registry does not guarantee that participants will be willing or eligible for prospective studies. Therefore, low cost means to dramatically increase enrollment will be essential to registry success. Alternative strategies, such as earned and social media campaigns, as well as email campaigns may enable more cost-effective methods for larger reach and should be studied.<sup>9</sup>

We did not find major differences among participants recruited through the differing postcards. Demographically, participants enrolled via the different postcard taglines were similar in age, sex, race, education, and medical history, including family history of AD. Subjective memory complaints were similar among the groups and notably greater than zero. Research attitudes were positive, and equally high among the groups. Although there were some apparent differences in enrollee willingness to be contacted about studies involving different procedures, such differences will require further study, especially given the overall low response rates here.

Other limitations of this study should be noted. Demographic information for the recipients of the postcards was not available, precluding specific assessment of selection bias among responders. Bias is apparent, nonetheless. For example, the local Orange County community is composed of approximately 34% Hispanic ethnicity and 21% Asian race,<sup>10</sup> but 77% of enrollees were non-Hispanic white. Whether the observed bias resulted from lower proportion of underrepresented racial and ethnic groups in the rented mailing lists vs. differences in responses rates is unknown. Similarly, we did not test whether differing postcard images (e.g., people of differing racial or ethnic backgrounds) could affect enrollment rates.

Despite these limitations, these results may be instructive for groups creating and recruiting to recruitment registries. Mailing postcards to local residents may not represent a cost-effective strategy for recruitment to an online registry. Future research should investigate whether electronic mailings (via email and social media) provide improved response rates and more cost effective use of resources.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## You may be eligible for Alzheimer's prevention studies at UCI! To find out, enroll in the UCI C2C Registry.

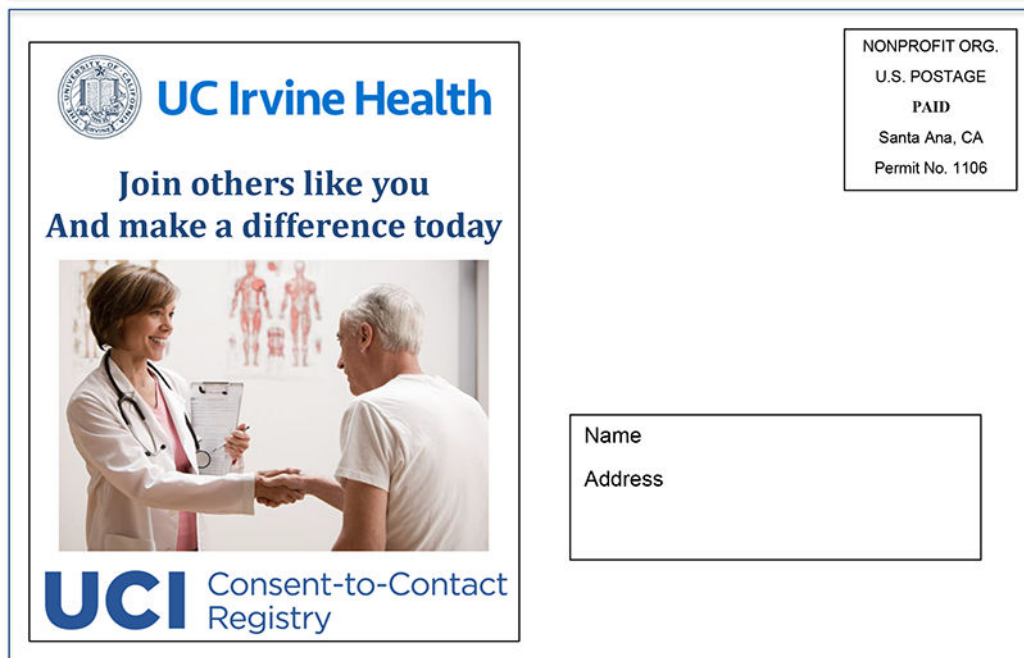
NIH-funded medical researchers at **UC Irvine** are working to better understand, diagnose, treat, and prevent Alzheimer's disease. The most consistent barrier to progress is slow recruitment to studies. If more people participated in research, medical advances would be made more rapidly.

The UCI Consent-to-Contact (C2C) Registry is a tool to help match interested people in Orange County with studies for which they might qualify, moving research faster toward cures. It is:

- Free
- Confidential
- Open to all Orange County adults, regardless of their healthcare provider
- Safe
- Carries no obligations

Signing up is easy. Join us today by visiting

<https://ad.c2c.uci.edu/>



**Figure 1.**  
Version 1a of postcards sent.

**Table 1.**

Responder characteristics by postcard type.

Participant Characteristics	Total (N=273)	General Research (N=56)	Brain Health (N=53)	AD Prevention (N=164)	p-value *
Number of postcards mailed	100,000	20,000	20,000	60,000	
% enrolled	0.27%	0.28%	0.27%	0.27%	0.97
Age, mean (SD)	65.7 (10.6)	64.2 (10.7)	67.0 (10.8)	65.7 (10.5)	0.37
Female sex, n (%)	162 (59.3)	30 (53.6)	34 (64.2)	98 (59.8)	
Race/ethnicity, n (%)					0.30
NH White	186 (77.2)	36 (70.6)	33 (73.3)	117 (80.7)	
NH Black	2 (<1)	0 (0)	1 (2.2)	1 (0.7)	
NH Asian	18 (7.5)	7 (13.7)	2 (4.4)	9 (6.2)	
Hispanic/Latino	31 (12.9)	8 (15.7)	7 (15.6)	16 (11)	
Other/mixed	4 (1.7)	0 (0)	2 (4.4)	2 (1.4)	
Education (years), n (%)					0.22
<12 (less than high school)	6 (2.2)	1 (1.8)	2 (3.8)	3 (1.8)	
12 (HS)	20 (7.4)	6 (10.7)	4 (7.6)	10 (6.1)	
13-15 (some college)	48 (17.7)	10 (17.9)	15 (28.3)	23 (14.1)	
16+ (college or higher)	198 (72.8)	39 (69.6)	32 (60.4)	127 (77.9)	
Number of medications, n (%)					0.68
None	50 (18.6)	14 (25.5)	6 (11.8)	30 (18.4)	
1-2	105 (39)	20 (36.4)	21 (41.2)	64 (39.3)	
3-4	53 (19.7)	11 (20.0)	12 (23.5)	30 (18.4)	
5	61 (22.7)	10 (18.2)	12 (23.5)	39 (23.9)	
Parental medical history, n (%)					
Cancer	99 (36.3)	20 (35.7)	17 (32.1)	62 (37.8)	0.75
Cardiovascular disease	90 (33.0)	24 (42.9)	13 (24.5)	53 (32.3)	0.12
Diabetes	17 (6.2)	8 (14.3)	1 (1.9)	8 (4.9)	0.02
Alzheimer's disease	36 (13.2)	5 (8.9)	6 (11.3)	25 (15.2)	0.44
CFI scores **, mean (SD)	2.9 (2.7)	2.3 (2.5)	3.4 (2.7)	2.9 (2.7)	0.12
RAQ scores ***, mean (SD)	28.0 (4.3)	27.8 (4.4)	28.6 (4.1)	28.5 (4.3)	0.50
Willingness to be contacted for studies, n (%)					
Approved medications	238 (87.8)	52 (92.9)	40 (76.9)	146 (89.6)	0.02
Investigational medications	209 (77.4)	47 (83.9)	33 (64.7)	129 (79.1)	0.04
Modify diet/physical activity	256 (94.1)	50 (89.3)	47 (90.4)	159 (97.0)	0.05
Blood draws	253 (93.0)	52 (92.9)	47 (90.4)	154 (93.9)	0.69
Cognitive testing	267 (98.9)	54 (96.4)	52 (98.1)	161 (100)	0.07
MRI scans	249 (91.9)	51 (91.1)	47 (90.4)	151 (92.6)	0.85
PET scans	220 (81.5)	48 (85.7)	38 (73.1)	134 (82.7)	0.20
Lumbar puncture	112 (41.5)	32 (58.2)	15 (28.9)	65 (38.9)	0.01
Autopsy	211 (77.6)	37 (66.1)	39 (75.0)	135 (82.3)	0.04

**Abbreviations:** NH= Non-Hispanic; RAQ= Research Attitude Questionnaire; CFI= Cognitive Function Inventory



\* P-values derived from omnibus chi-square tests for categorical variables and analysis of variance (ANOVA) for continuous variables.

\*\* Higher scores indicate more subjective complaints

\*\*\* Higher scores indicate more positive research attitudes

All percentages are based on non-missing data.

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