



UCI Consent-to-Contact Registry

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A new tool for accelerating clinical research recruitment at UCI

Introduction

The most consistent barrier to improved medical care is slow recruitment to clinical research. To help clinical investigators at UCI overcome this barrier, we developed a potential participant registry. The UCI Consent-to-Contact Registry (C2C, c2c.uci.edu) is an online repository of individuals who have given permission to be contacted about studies for which they may be eligible. The objective of the registry is to enhance clinical research recruitment at UCI. Investigators from all departments and schools have the opportunity to recruit through the registry, provided that they have IRB approval to do so and complete the necessary components to access the registry with the organizers.

Methods

The C2C is an IRB-approved source for study recruitment. Interested community members can enroll at one of two levels:

1. Email only—to receive information on studies in general;
2. Full enrollment with electronic informed consent—to be matched with suitable studies.
 - Self-reported demographic, diagnostic, and medical information.
 - Validated diet, exercise, memory performance, and research attitude scales.
 - Research willingness (e.g., types of studies).
 - Annual renewal.

- Enrollment methods: community outreach, media and press coverage, and web-based outreach.
- Engagement and retention strategies: e-newsletters and promotional items.

UCI investigators with IRB-approved protocols can:

1. Submit study information to be emailed to level one registrants OR
2. Request a query of level two registrants:
 - List the C2C as a source of participants in IRB protocol narrative.
 - Provide inclusion/exclusion for registry criteria.
 - Receive query results (n=50, with multiple queries permitted).
 - Comply with requirements for communicating query results.

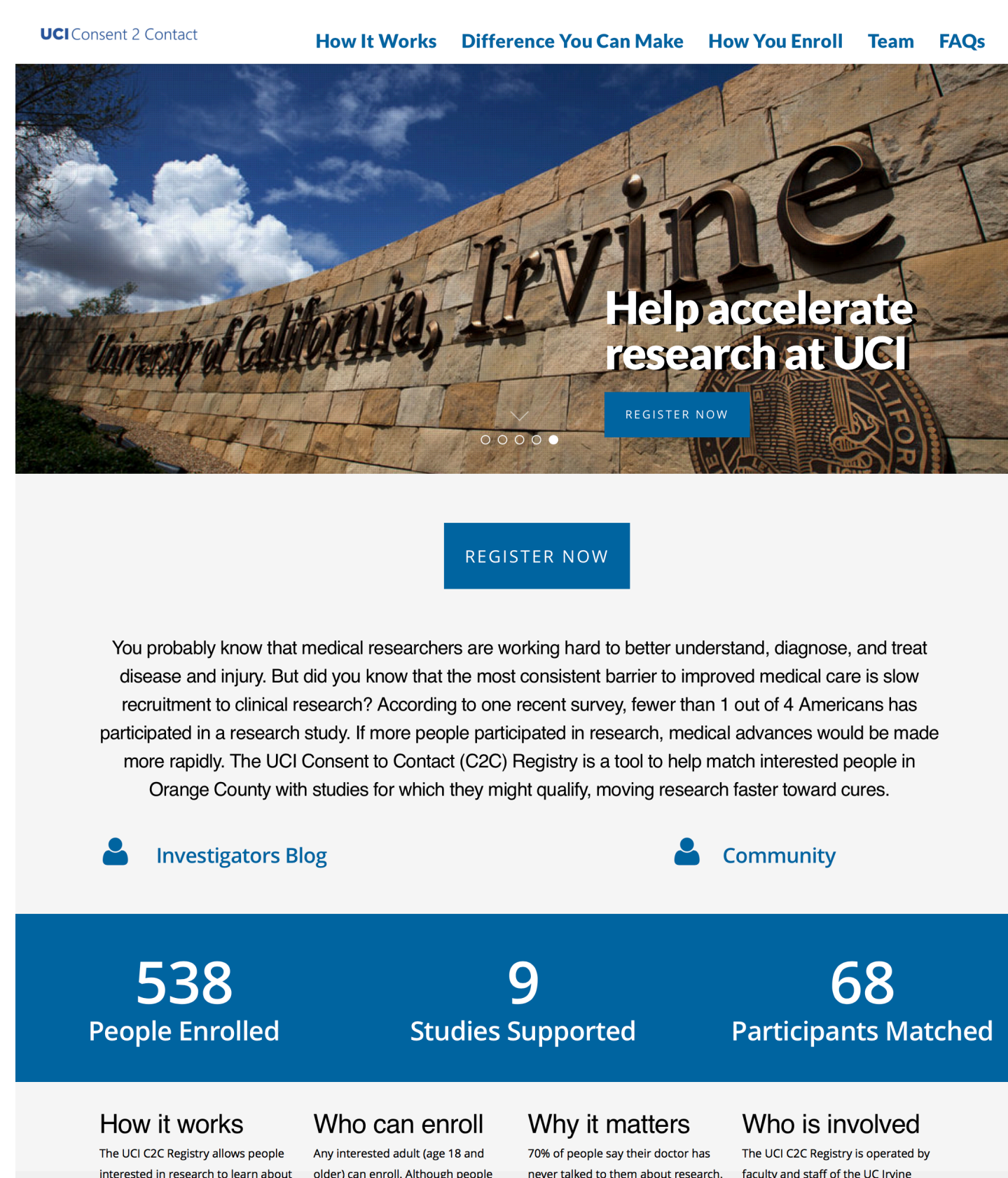


Figure 1. UCI C2C homepage, accessed 6/5/17.

Results

Enrollment

- As of June 5, 2017, 864 adults have registered in the C2C, of which 304 provided email only and 538 provided demographic and health data (Figure 2).

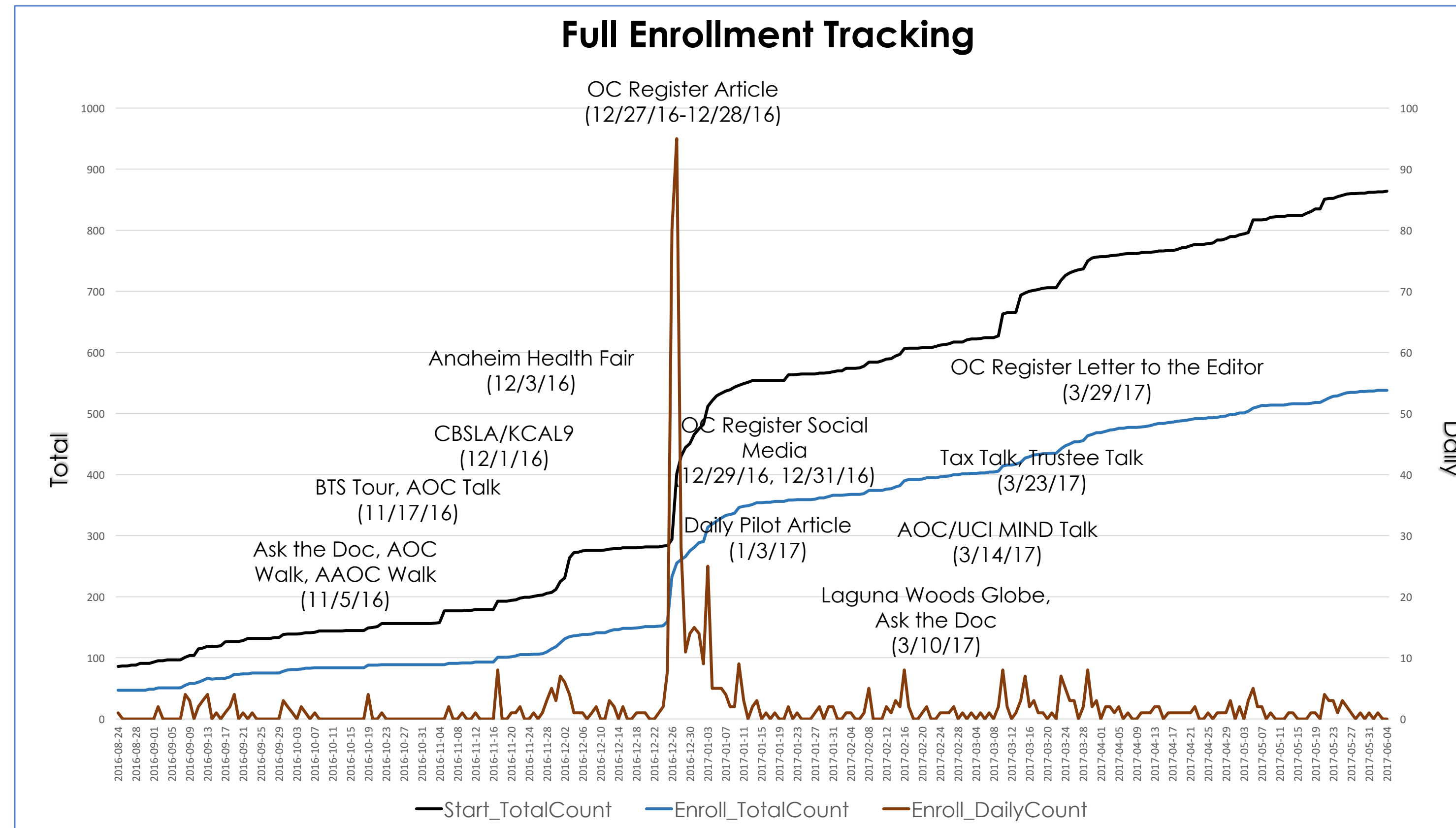


Figure 2. Accrual over time. Cumulative level 2 (blue) and total (level 1 and 2, black line) accrual is plotted. Daily enrollment (red) is also plotted, with days with >10 started enrollments indicated by labels of chronologically matched recruitment efforts.

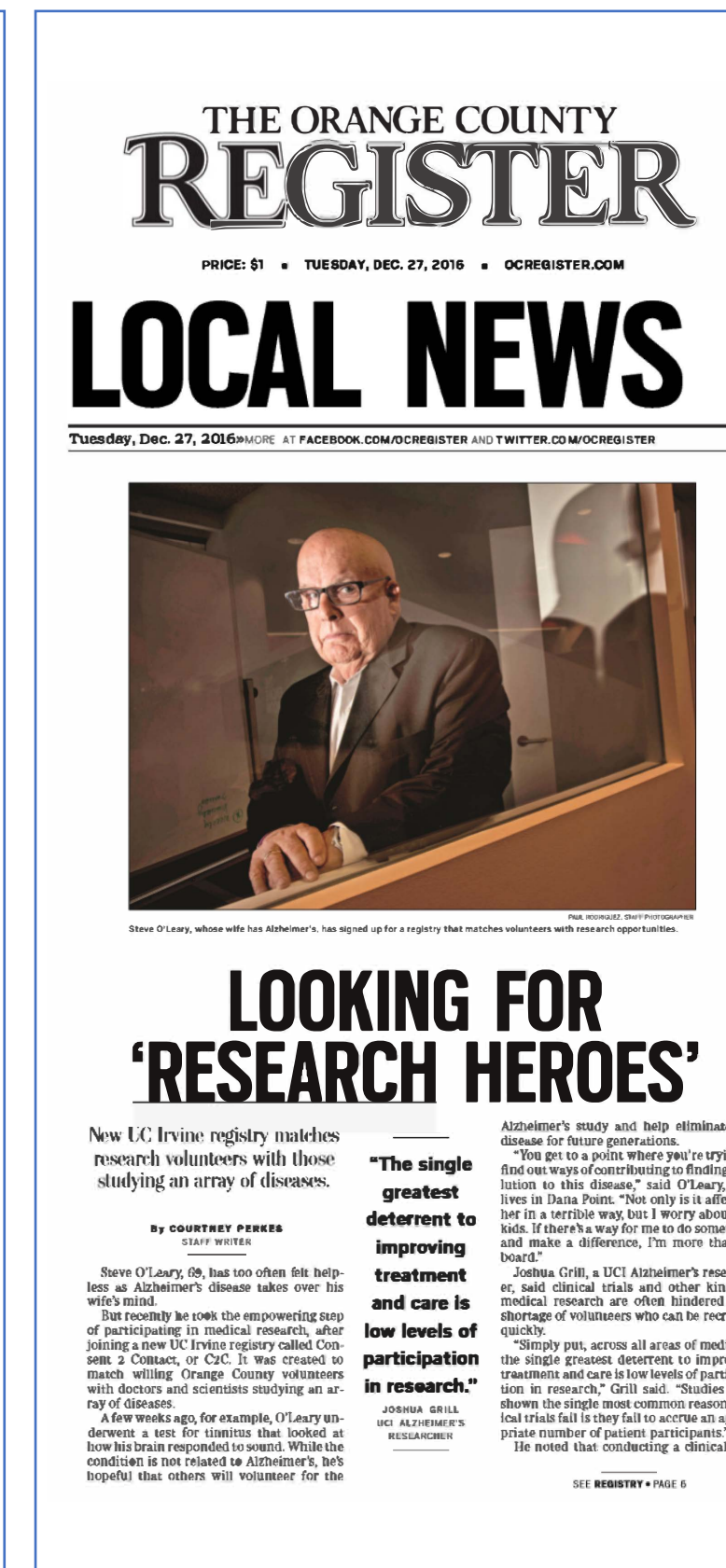


Figure 3. Example of earned media.

Table 1. Participant Sources, n (%)

Newspaper	194 (37.6)
Community Talk	103 (20.0)
Other	100 (19.4)
Friend Referral	76 (14.7)
Online Search	17 (3.3)
Social Media	11 (2.1)
Television Story	6 (1.2)
Radio PSA	5 (1.0)
Doctor Referral	4 (0.8)

Enrollee Demographics

- 521 (97%) enrollees are interested in studies at UCI campus, while 469 (88%) are interested in studies at UCI Medical Center in Orange (Table 3).

Table 2. Characteristics of full enrollees (n=538)

Age, median years (SD) [Range]	68.5 (15.66) [18-97]
Female, n (%)	357 (66)
White race, n(%)	431 (86)
Education, mean years (SD) [Range]	16.77 (5.89) [5-26]
Medications, mean n (SD) [Range]	3.02 (2.92) [0-20]
Weight, mean lb (SD) [Range]	162.89 (36.01) [85-290]
Height, mean cm (SD) [Range]	168.70 (10.02) [140-193]
RAQ, mean (SD) [Range]	29.83 (3.75) [7-35]

RAQ, Research Attitude Questionnaire.

Table 3. Willingness to undergo procedures, n (%)

Blood Draw	502 (95)
MRI	506 (94)
Approved Medication	469 (88)
Investigational Medication	469 (88)
PET	450 (84)
Autopsy	419 (78)
Lumbar Puncture	219 (41)

MRI, Magnetic Resonance Imaging. PET, Positron Emission Tomography.

Effectiveness

- UCI investigators have requested C2C queries resulting in 292 eligible registrants from which 49 have been matched and enrolled in four IRB-approved studies, with an additional five studies pending screening of 78 registrants (Table 4).

Table 4. Studies and enrollees matched

Study	Study #	= Identified, n	= Unable to reach, n (%)	= Declined participation, n (%)	= Ineligible through phone screen, n (%)	= Enrolled, screen failed, n (%)	= Enrolled, eligible, n (%)
Hearing study	1	50	27 (54)	7 (14)	4 (8)	4 (8)	8 (16)
Hearing clinical trial	2	28	11 (39)	0 (0)	0 (0)	1 (4)	16 (57)
Alzheimer's prevention trial	3*	86	20 (23)	33 (39)	13 (15)	6 (7)	14 (16)
Alzheimer's prevention trial	4*	50	9 (18)	9 (18)	7 (14)	TBD	TBD

* Screening in progress

Future Plans and Areas of Need

- Recruitment will continue and enroll throughout Orange County (Figure 4).

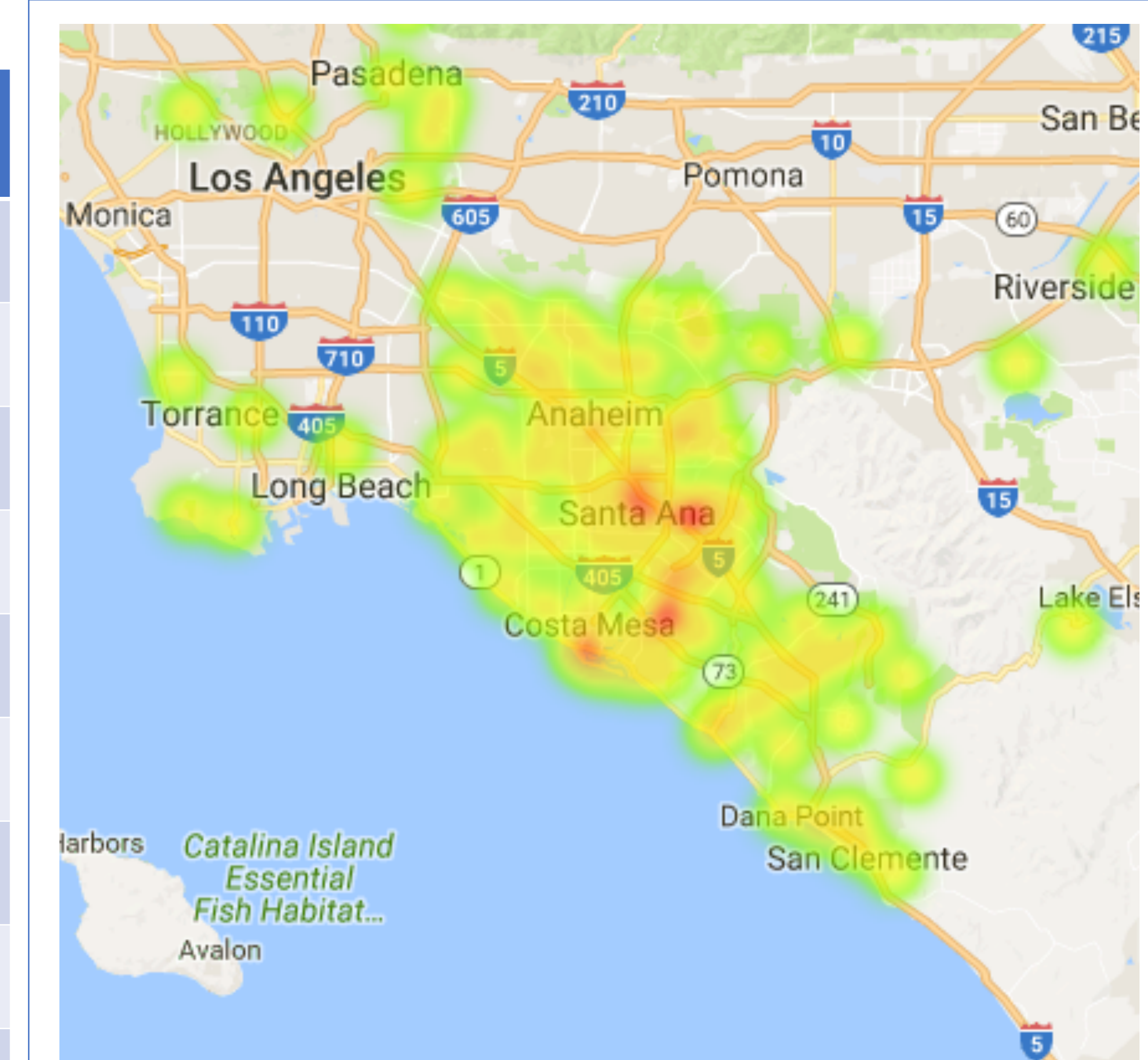


Figure 4. Google heat map of enrollee zip codes.

- Facebook advertising campaigns are underway that stagger ads describing C2C as an Alzheimer's prevention registry or a general research registry (Figure 5).

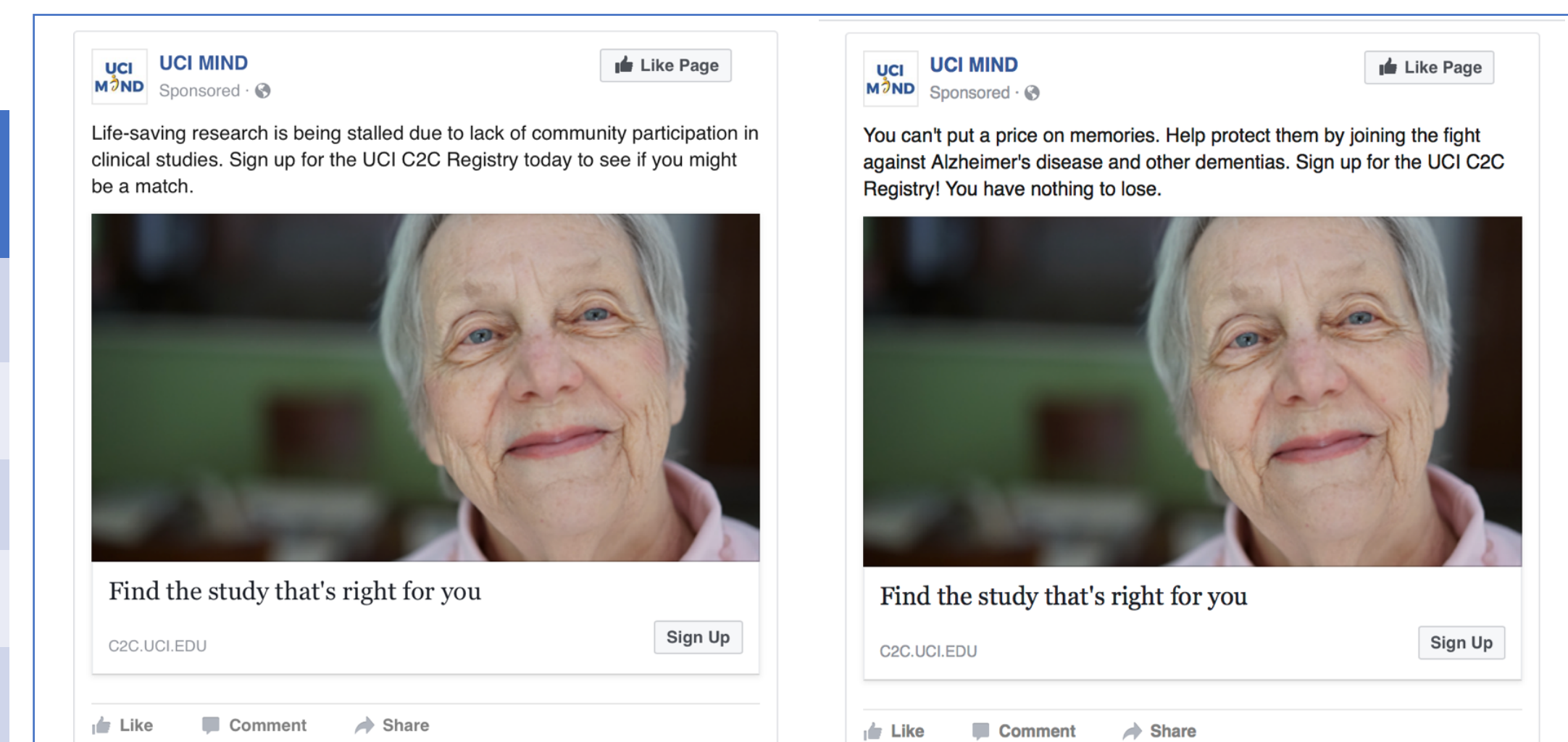


Figure 5. Ongoing Facebook advertising tests of general health (left) vs. Alzheimer's-specific (right) ad text.

- Several methods of engagement are being used or planned, including: tokens of appreciation, semi-annual newsletters, and patient-centered research surveys.
- The registry is less than one year old, therefore annual renewal data are not yet available for analysis.

Conclusions

- C2C is an important tool to facilitate recruitment to clinical research at UCI.
- To learn more about the C2C or begin utilizing it for an IRB-approved study, contact Adrijana Gombosov (agombosov@uci.edu) or Kirsten Klein (kleinkm@uci.edu).

Acknowledgements

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