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Diversifying recruitment registries: Considering neighborhood health metrics

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Abstract

Background: Disparities in clinical research participation perpetuate broader health disparities. Recruitment registries are novel tools to address known challenges in accrual to clinical research. Registries may accelerate accrual, but the utility of these tools to improve generalizability is unclear.

Objective: To examine the diversity of a local on-line recruitment registry using the Area Deprivation Index (ADI), a publicly available metric of neighborhood disadvantage.

Design: Retrospective analysis.

Setting: Data were collected in the University of California Irvine Consent-to-Contact Registry.

Participants: We categorized N=2,837 registry participants based on the ADI decile (collapsed into quintiles) using a state-based rankings.

Measurements: We examined the proportion of enrollees per ADI quintile and quantified the demographics of these groups. We assessed willingness to participate in studies involving unique research procedures among the ADI groups.

Results: Although registry enrollees represented the full spectrum of the ADI, they disproportionately represented less disadvantaged neighborhoods (lowest to highest quintiles: 42%, 30%, 15%, 6%, 7%). Compared to participants from less disadvantaged neighborhoods, participants from more disadvantaged neighborhoods were more often female, of non-white race, and Hispanic ethnicity. Despite demographic differences, ADI groups were observed to have similar willingness to participate in research studies.

Conclusions: People from more disadvantaged neighborhoods may be underrepresented in recruitment registries, increasing the risk that they will be underrepresented when using these tools to facilitate prospective recruitment to clinical research. Once enrolled in registries, participants from more disadvantaged neighborhoods may be equally willing to participate in research. Efforts to increase representation of participants from disadvantaged neighborhoods in registries could be an important first step toward increasing the generalizability of clinical research.

Keywords

Registry; recruitment; neighborhood; diversity; disparities

Introduction

Clinical research is rarely inclusive of populations that reflect the full US population. (1, 2) To address disparities in participation, researchers should consider applying recruitment approaches that are responsive to the mechanistic lens provided by the breadth of the National Institute on Aging Health Disparities Framework (<https://www.nia.nih.gov/research/osp/framework>). One of these considerations is socioeconomic contextual disadvantage, or “neighborhood disadvantage.” This construct can be measured using the census block-group level Area Deprivation Index (ADI), a marker for social determinants of health within these discrete geo-areas that may promote or impair human health such as employment, income, education and housing quality factors.(3, 4) The most disadvantaged neighborhoods in the US as measured by ADI tend to have higher proportions of African American/Black, Hispanic and Native American residents; are often located within inner city urban or highly rural areas; and tend to have higher rates of complex chronic medical conditions like heart disease, diabetes and chronic pulmonary disease. Higher ADI is associated with poorer late life health outcomes,(5–8) including risk for Alzheimer’s disease and related dementias (ADRD).(9–11) ADI is available freely to the public through the University of Wisconsin Neighborhood Atlas, a customizable mapping and data platform that makes this information easily accessible to investigators recruiting to prospective clinical research studies.(3, 12)

Recruitment registries are relatively new tools meant to address a crisis in ADRD clinical research recruitment.(13) Registries enroll large populations of potentially eligible and willing participants for research studies, in an effort to accelerate accrual to new studies once they begin. Several questions remain about the effectiveness of these tools,(14) especially as it relates to diversifying research populations.(15–17) We developed the UC Irvine Consent-to-Contact (C2C) Registry, a local on-line recruitment registry in Orange County, California. (18) Multiple strategies have been applied to enroll participants in the C2C Registry, including community, direct mail, and electronic outreach.(18, 19) As yet, these strategies

have not included specific geo-targeted approaches. In this exploratory study, we examined the representativeness of C2C Registry, based on state ADI deciles. To our knowledge, this is the first assessment of ADI within a recruitment registry. We also assessed whether specific recruitment techniques were more frequently sources of high ADI participants and whether ADI was associated with stated research preferences when enrolling in the C2C Registry.

Methods

Data source and participants.

We performed an exploratory descriptive analysis of the C2C Registry for outcomes related to ADI using data from participants enrolled on or before 09/29/2020. This local on-line recruitment registry was developed and launched in 2016 to accelerate accrual to clinical research studies at the University of California Irvine (UCI), with a particular emphasis on preclinical AD trials.(18) To be eligible for the C2C, participants must be 18 years of age or older. All participants provided informed consent electronically. Registry enrollment requires completion of demographic and clinical questionnaires on-line, estimated to take approximately 20 minutes to complete. Demographic and clinical information is self-reported and has been described previously.(18) Participants self-described race and ethnicity, queried as separate categories, each offering a “prefer not to answer” option. Recruitment sources were captured at enrollment and included earned media, community outreach activities, postcard mailings, e-mail, Internet, social media, and referrals from physicians or others. Nine questions determined enrollee’s willingness to be contacted for studies that involve: (1) modification of diet or physical activity, (2) cognitive testing, (3) blood draws, (4) magnetic resonance imaging (MRI), (5) positron emission tomography (PET) imaging, (6) FDA approved medications, (7) investigational medications, (8) lumbar puncture (LP), and (9) autopsy. Research attitudes were assessed by the validated Research Attitude Questionnaire (RAQ(20)), which uses Likert scales to examine participants’ agreement with 7-items, scored 1–5 (Range: 7–35), with higher scores indicating more positive research attitudes. Enrollees also complete the Cognitive Function Instrument (CFI), a 14-item measure of subjective cognitive performance (Range: 0–14), with higher scores indicating more complaints.(21, 22)

ADI assessment.

We used C2C enrollees’ permanent addresses to determine their ADI. The ADI incorporates 17 measures originally drawn from the long-form Census related to education, employment, housing-quality, and poverty,(7) to rank the deprivation of US census block groups (~1500 people). From these, an index ranking is created to compare a specific census block to state or national norms, typically presented as deciles.(3)

The ADI can be used for research purposes. For example, using the ADI based on 2000 Census data, Kind et al(7) found that the risk of living in a disadvantaged neighborhood is similar to that of having a chronic lung disease, like emphysema, and worse than that of health conditions such as diabetes when it comes to readmission risk. Using the ADI, Joynt Maddox and colleagues(23) added social risk factors including neighborhood disadvantage

to models used to calculate penalties under the CMS's Hospital Readmission Reduction Program. They found that accounting for these factors had a major impact on safety-net hospitals that serve patients from the most disadvantaged neighborhoods; over half would have seen a decline in their readmission penalty if such an adjustment had been applied. Most recently, the ADI has also been employed for COVID vaccine allocation in a number of US states as a means by which to most efficiently and effectively allocate resources to areas of greatest need.(24)

To use the ADI, we downloaded the data through the Neighborhood Atlas (<https://www.neighborhoodatlas.medicine.wisc.edu/>) and linked to C2C enrollee addresses using 12-digit Federal Information Processing Standards (FIPS) code via the US Census Bureau Geocoder (<https://geocoding.geo.census.gov/>). C2C records with a 12-digit FIPS code were then matched to a locally download California 2015 ADI v2 dataset where ADI scores were obtained.

All ADI were calculated at the block group level. We examined C2C enrollees' ADI using state-based norms. Adequate information to determine ADI was missing for N=1284 records (e.g. providing a PO Box, rather than a street address at enrollment). We also compared the C2C ADI distributions to the larger Orange County population, using data from the 2019: American Communities Survey 5-Year Estimates Detailed Tables (<https://data.census.gov/cedsci/>).

Ethics.

The Institutional Review Board at UCI approved this study.

Analyses.

We assessed the relative representation of ADI deciles among enrolled C2C participants. We hypothesized that high ADI participants are underrepresented in this recruitment registry. We used geocoding maps to illustrate the distribution of ADI decile representation among C2C enrollees. We used descriptive statistics (mean and standard deviation for continuous responses, and frequency and percentage for discrete responses) to summarize the demographic characteristics of C2C enrollees by ADI, discretized into California state-specific quintiles. We further quantified willingness to participate across ADI quintiles. To do so, we characterized the frequency with which individuals from the differing ADI categories agreed to be contacted about studies that required the nine research procedures noted above. Given the descriptive nature of the research presented, inferential statements are not presented to avoid over-interpretation of exploratory results.

Results

Among 4315 participants enrolled in the C2C Registry as of 09/29/2020, sufficient data were available for 2759 to link to the ADI. The supplementary table compares those with ADI information to those lacking it. Though no major differences were apparent between these groups, the group lacking ADI information was less often of white race (78% vs 83%), less often had two or more comorbidities (37% vs. 42%), and less often took three or more concomitant medications (40% vs. 50%). Among those with available ADI information,

each of the ADI deciles was represented, though the distribution of enrollees was skewed toward lower deprivation. Forty-two percent of enrollees resided in the lowest ADI quintile (i.e., least neighborhood disadvantage), compared to only 7% and 6% in the highest and second-highest ADI quintiles (Figure 1A). In contrast, the distribution of ADI strata among all Orange County residents was skewed toward more disadvantaged neighborhoods, in particular for the tenth ADI decile. Figure 1B illustrates the geographic spread of C2C enrollees, coded by their ADI decile.

Individuals from the highest ADI quintiles were observed to be more often female and to more often self-report being from a non-white race or Hispanic ethnicity (Table 1). Participants from the lowest ADI quintile had the highest average level of education. The lowest ADI quintile had the lowest proportion of participants self-reporting three or more comorbid medical conditions. Recruitment sources were similar across the ADI groups, although email produced less than half of the registrants in the highest ADI quintile, compared to 51–61% of the lower quintiles. CFI scores were observed to be lowest in the lowest ADI quintile and highest in the highest ADI quintile. RAQ scores were similar across the ADI groups.

The proportions willing to be contacted about studies among the ADI quintiles were highly consistent for each research procedure (Table 2). Across ADI categories, the proportions willing to participate were highest for research requiring cognitive testing and lowest for research requiring lumbar puncture.

Discussion

ADRD research faces critical challenges in recruiting samples that ensure generalizable results. Participants are consistently young, well educated, and from high socioeconomic status, compared to the general population.⁽²⁵⁾ In this study, we examined socioeconomic diversity using the ADI in our local on-line recruitment registry, an example of an increasingly utilized tool to accelerate clinical research accrual. We found that participants in our registry were representative of all strata of the ADI but, as we hypothesized, were disproportionately from the lowest ADI strata (least disadvantaged neighborhoods). As has been noted in previous studies,⁽¹²⁾ participants from high ADI strata were more frequently of non-white races and Hispanic ethnicity. Education levels were notably high among all ADI strata and we observed no differences in the overall willingness to participate in research. This finding may suggest that registries, in particular those registries that are effective in recruiting high ADI participants, may offer a valuable opportunity to diversify ADRD studies.

There are numerous important implications to these findings. Ensuring the diversity of clinical research studies, especially clinical trials of new therapies, is a critical area of need. Relatively few research participants are non-white race or Hispanic ethnicity,^(26, 27) despite African Americans and Hispanics being at greatest risk for dementia.⁽²⁸⁾ Biased homogeneous samples limit generalizability and risk misunderstanding of effect modification of treatment safety or efficacy.⁽²⁹⁾ Barriers to registry recruitment may be lower than barriers to participation in clinical studies,⁽³⁰⁾ since the risks and requirements

are generally modest. This may create an opportunity to enroll diverse populations in registries for the purpose of engaging them and increasing participation in clinical research studies.(15) The current results may suggest that geotargeted recruitment efforts will be essential to increasing the diversity of registry participants and that successfully doing so may permit careful selection for recruitment to prospective studies to ensure representation of different socioeconomic groups, since ADI strata were equally willing to be contacted about types of research studies. Further research is needed, however, to understand whether barriers to recruitment to registries may differ among ADI strata. While we observed associations between ADI and race and ethnicity, other social determinants of health, such as direct measures of socioeconomic status, acculturation, and racism all may be critical to understand and address.(25, 31)

The inclusion of more disadvantaged neighborhoods is an important consideration to ADRD recruitment efforts. The digital divide is narrowing, with most US adults having smartphones.(32) This may create opportunities to use social media and electronic campaigns to better reach people from disadvantaged communities.(33) To date, we have engaged in minimal effort to recruit to the C2C Registry through digital tools, but other work points to the potential utility of social media and other on-line recruitment strategies. (34–37) Alternatively, more traditional recruitment approaches such as direct mail(38) and grassroots education(39, 40) present clear opportunities to target specific neighborhoods. Though our previous direct mail campaigns produced lower yield than expected, this method has been successful in other registries(13) and we did not previously test for potential effect modification by ADI.(38) We also note new opportunities to enhance the use of direct mail, such as “quick response (QR)” codes that enable recipients to open a link or install an application using the camera on their cell phone or tablet device as a barcode-reader.

Although our registry does not perform objective cognitive testing, as do some others,(41, 42) it has other important strengths. Participants in our registry provide self-reported data on cognitive performance using the CFI, which has been shown to differ among preclinical AD participants and biomarker negative controls.(21, 43) Intriguingly, CFI scores were elevated among the high ADI group in the C2C Registry. This observation is similar to previous cross sectional(12) as well as longitudinal studies of cognitive performance.(11) Although we have no data to consider potential mediators of these subjective complaints, it is conceivable that complaints could be driven by differences among the groups in brain volume(10, 44) or even AD neuropathology,(9) reaffirming the potential importance of recruiting these groups to prospective research studies, such as preclinical AD trials.

Lack of differences among ADI strata were also important, including the lack of differences in willingness to be contacted about studies and for the RAQ. Work at other academic researcher centers engaged in community outreach has found that RAQ scores were lower among diverse communities, compared to more traditional research populations.(45) Previous analyses of the diverse racial and ethnic groups that make up C2C Registry observed similar differences,(17) but we found no such differences based on neighborhood disadvantage here. Future work should aim to elucidate relationships among other social determinants of health and research attitudes.

We note some important limitations of the current study. We did not have sufficient data to assess ADI on every registrant due to data missingness and some participants including only a PO Box address at enrollment. We are unable to assess whether missingness due to this factor is at random or more disproportionately affects specific ADI strata. If missingness were more prominent among high ADI strata, it might suggest that these data overestimate the underrepresentation of high ADI participants, but create more uncertainty about the examination of these participants in particular (e.g., their willingness to participate). We also acknowledge that self-reported willingness to be contacted about studies is not equivalent to the behavior of participating in a study. From our registry, we have referred participants to a large variety of studies and consistently achieve >30% enrollment of referred individuals. We cannot rule out that, despite similarities in indicated willingness, differences among ADI strata in actual study enrollment could still exist. Similarities in RAQ scores across ADI strata may argue against this possibility, however, and future research will examine this question.

In conclusion, people from more disadvantaged neighborhoods may be underrepresented in recruitment registries, increasing the risk that they will be similarly underrepresented when using these tools to facilitate prospective recruitment to clinical research. Once enrolled in a registry, these data suggest that participants from more disadvantaged neighborhoods may be equally willing to participate in research. Efforts to increase representation of participants from disadvantaged neighborhoods in registries could therefore be an important intervention to increase generalizability in clinical research studies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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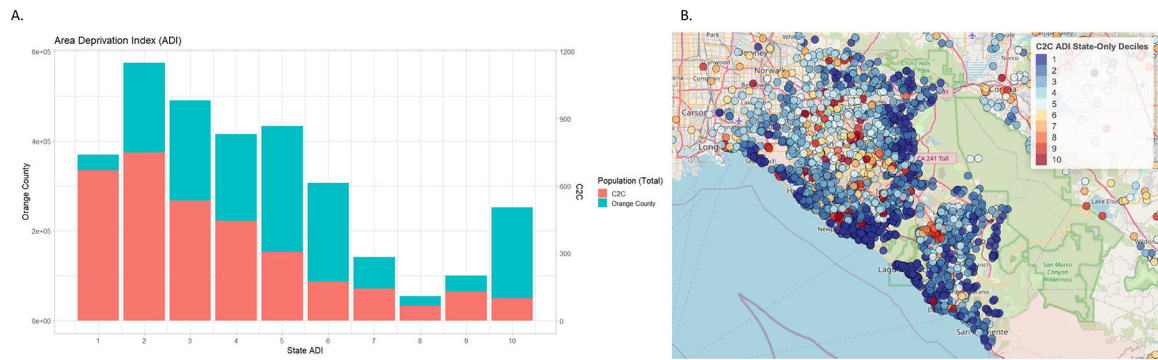


Figure.
 (A) Histogram plots of the relative proportions of ADI categories for C2C Registry enrollees (in orange, right-hand y-axis) and for the overall population in Orange County (blue, left hand y-axis). (B) Geocoded map of enrollees in the C2C Registry based on their state ADI index. Illustrated dots represent individual enrollees with added noise, using the R Jitter function, to protect participant confidentiality. ADI, Area Deprivation Index; C2C, Consent-to-Contact

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Table 1.

Demographic and clinical characteristics of C2C enrollees across ADI categories.

Study Type	State ADI Group				
	1-2 (N=1185)	3-4 (N=824)	5-6 (N=403)	7-8 (N=163)	9-10 (N=184)
Age in years, mean (SD)	60.8 (14)	58.0 (16)	53.5 (16)	55.8 (17)	57.1 (18)
Female sex, n (%)	733 (62)	499 (60)	276 (68)	103 (63)	132 (72)
Race					
White, n (%)	1040 (88)	680 (82)	322, (80)	118 (72)	133, (72)
Black/Af Am, n (%)	6 (0.5)	8 (1)	7 (2)	4 (2)	12 (6)
Asian, n (%)	78 (6.6)	54 (7)	17 (4)	9 (5)	17 (9)
More than one race, n (%)	22 (2)	22 (3)	17 (4)	11 (7)	6 (3)
Other*	39 (3)	60 (7)	40 (10)	21 (13)	16 (9)
Hispanic ethnicity	55 (5%)	80 (10)	85 (21)	31 (19)	29 (16)
Years education, mean (SD)	17.1 (5.5)	16.3 (5.1)	15.8 (2.9)	15.9 (3.1)	16.3 (5.9)
Comorbidities, n					
0, n (%)	363, (31)	232 (28)	111 (27)	36 (22)	51 (28)
1, n (%)	352 (30)	258 (31)	104 (26)	56 (34)	45 (24)
>=2, n (%)	470 (40)	334 (40)	188 (47)	71 (44)	88 (48)
Medications, n	N=1167	N=809	N=398	N=162	N=183
0, n (%)	222 (19)	156 (19)	81 (20)	26 (16%)	37 (20)
1, n (%)	170 (15)	124 (15)	78 (20)	27 (17)	21 (11)
2, n (%)	189 (16)	121 (15)	50 (13)	22 (14)	36 (20)
>=3, n (%)	586 (50)	408 (50)	189 (47)	87 (54)	89 (49)
CFI, mean (SD)	2.6 (2.8)	3.1 (3.0)	3.4 (3.1)	3.3 (3.1)	3.5 (3.1)
RAQ, mean (SD)	28.8 (4.1)	28.3 (4.6)	28.7 (4.2)	28.3 (5.3)	28.1 (4.5)
Recruitment source					
Physician referral, n (%)	44 (4)	42 (5)	15 (4)	10 (6)	11 (6)
Community outreach, n (%)	150 (13)	61 (7)	16 (4)	20 (12)	17 (9)
Earned media, n (%)	38 (3)	25 (3)	17 (4)	9 (5)	4 (2)
Internet, n (%)	45 (4)	38 (5)	24 (6)	6 (4)	10 (5)
Social media, n (%)	16 (1)	10 (1)	12 (3)	3 (2)	4 (2)
Friend referral, n (%)	79 (7)	43 (5)	24 (6)	9 (5)	11 (6)
Email, n (%)	627 (53)	463 (56)	248 (61)	83 (51)	91 (49)
Postcard, n (%)	93 (8)	70 (8)	30 (7)	9 (5)	16 (9)
Other, n (%)	83 (7)	69 (8)	16 (4)	13 (8)	20 (11)

* includes American Indian or Alaska Native, Native Hawaiian or Pacific Islander, those who refused, and missing.

Table 2.

Willingness to participate across ADI categories in the C2C Registry.

Study Type	State ADI Group				
	1-2 (N=1185)	3-4 (N=824)	5-6 (N=403)	7-8 (N=163)	9-10 (N=184)
Approved Med, n (%)	1024 (87)	703 (86)	348 (86)	143 (88)	164 (89)
Investigational Med, n (%)	924 (79)	632 (77)	310 (77)	126 (77)	143 (78)
Diet/Lifestyle, n (%)	1114 (94)	761 (93)	373 (93)	148 (91)	171 (93)
Blood Draws, n (%)	1121 (95)	748 (91)	369 (92)	149 (91)	177 (96)
Cognitive Tests, n (%)	1164 (99)	788 (96)	387 (97)	155 (96)	182 (99)
MRI, n (%)	1103 (93)	759 (92)	377 (94)	151 (93)	169 (92)
PET, n (%)	970 (83)	661 (81)	335 (83)	122 (76)	150 (81)
Lumbar Puncture, n (%)	484 (41)	355 (43)	183 (45)	68 (42)	92 (50)
Autopsy, n (%)	850 (72)	569 (69)	282 (70)	107 (66)	132 (72)

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