Research and Engagement Strategies for Young Adult Immigrants Without Documentation: Lessons Learned Through Community Partnership

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Abstract

Background: Limited research has focused on undocumented immigrants' health and access to care.

Objectives: This paper describes participant engagement strategies used to investigate the health needs of immigrants eligible for Deferred Action for Childhood Arrivals (DACA).

Methods: Community-based strategies engaged advocates and undocumented Californians in study design and recruitment. Outreach in diverse settings, social media, and participant-driven sampling recruited 61 DACA-eligible focus group participants.

Lessons Learned: Social media, community-based organizations (CBOs), family members, advocacy groups, and participant-driven sampling were the most successful recruitment strategies. Participants felt engaging in research was instrumental for sharing their concerns with health care providers and policymakers, noteworthy in light of their previously identified fears and mistrust of government officials.

Conclusions: Using multiple culturally responsive strategies including participant-driven sampling, engagement with CBOs, and use of social media, those eligible for DACA eagerly engage as research participants. Educating researchers and institutional review boards (IRBs) about legal and safety concerns can improve research engagement.

Keywords

Community-based participatory research, community health research, health disparities, vulnerable populations, health care reform, medical indigency, social class, medically uninsured

The population of immigrants in the United States is an estimated 41.7 million, 11.7 million of whom are undocumented.[1] Undocumented immigrants have received increased media and public policy attention over the past several years as Congress debated immigration reform and the presidential programs for DACA and Deferred Action for Parents of Americans and Lawful Permanent Residents (DAPA) were introduced.[2] These programs allow beneficiaries to live and work temporarily, without threat of deportation.[2] The DACA program, implemented in 2012, specifically targets young people who immigrated as children, have been living otherwise lawfully, and have attained certain educational goals (Table 1).[3] Efforts to implement DAPA and expand the age range and duration of DACA have been challenged in federal court. Their future remains uncertain, although the US Citizenship and Immigration Service anticipates accepting DAPA applications later in 2015.[4] Adding to uncertainty, applicants who do not receive DACA expose their own and their family's immigration status without subsequent protections. DACA applications are also complex and expensive, frequently requiring the services of immigration attorneys and a $465 application fee.[5]

Previous research has demonstrated health disparities between immigrants and US natives. Disparities, worse among undocumented populations, include high rates of obesity, later presentation of illnesses such as human immunodeficiency

virus infection and cancer, lower rates of preventative screening, and poor access to care.[6–12] Undocumented immigrants are particularly vulnerable to mental health conditions such as trauma, depression, and anxiety, and face even greater limits on access to mental health care.[13–16] Much of the data on the health of undocumented immigrants focuses on older adults or children. There is a dearth of research on the health and health care access of the population of 14- to 31-year-olds who are eligible for DACA, often referred to as DREAMers because they were the target population for the 2011 *Development, Relief, and Education for Alien Minors Act*.[17] It is important to study this population specifically because policy changes such as DACA are likely to improve their access to health care and impact their health outcomes. In the first published study of the health and health care access of those eligible for DACA, our team identified highly limited access to primary care, mental health care, and specialty care, compounded by poor health care literacy.[15] Participants also reported histories of trauma, depression, and anxiety.[15] Despite these needs, DREAMers are explicitly excluded from accessing public or private health insurance through the Affordable Care Act.[18] By 2016, 62% of undocumented adults are expected to remain uninsured, making it critical to engage with DACA-eligibles to understand their health concerns and how they are accessing care.[19]

Research engagement with immigrants is quite challenging owing to mistrust of medical professionals, power differentials between researchers and participants, difficulty penetrating isolated communities, language barriers, and small available sample sizes.[15,20,21] Research recruitment of undocumented populations is even more challenging given fears related to engagement with government and health care organizations, concerns about disclosing documentation status, discrimination, and competing economic and social demands for their time.[15,16,22–24] Community-based recruitment has been successful in some studies with broader Latino samples and is likely to be critical to research with subsets of immigrant populations such as those without documentation.[9,20,21,25,26]

As a difficult-to-reach and understudied population, it is also important to elucidate how to engage them, not only in available health care programming, but also in research that contributes to the development of policies that improve their health care access. This paper details the participant engagement strategies and research challenges of a research team studying DACA-eligible Latinos.

Table 1. Eligibility Criteria for the Deferred Action for Childhood Arrivals Program

Must be under 31 years old as of June 15, 2012.*
Must have immigrated to the United States before 16 years of age.
Must have resided in the United States continuously since June 15, 2007.
Must have no felony convictions, serious misdemeanors, and fewer than three misdemeanors.
Must currently attend school, have a high school diploma or General Equivalency Diploma (GED), or have been honorably discharged from the United States military.

*This requirement has been suspended in the 2015 program requirements.

METHODS

Drawing on principles of community-based participatory research, we recognized the unique identity, strengths, and challenges faced by the undocumented community and sought to engage community stakeholders and DREAMers in a collaborative partnership in this study's design, participant recruitment, and validation of findings.[27,28] This approach allowed us to gain an understanding of the community's health concerns and health care access (published elsewhere[15]), while also co-learning with DREAMers and community advocates about how to most effectively engage this population in research.[17]

We recruited a 10-member advisory board via snowball sampling beginning with immigration policy contacts through the Labor Centers at the University of California Berkeley and Los Angeles. These well-connected stakeholders worked with the research team to recruit DREAMers, community advocates, researchers, and health care providers from across the state. The board informed the research team about recruitment strategies and potential community partner organizations through quarterly conference calls and ongoing email feedback. Members of the board were integral in identifying and recruiting the study's DREAMer interns. The board also provided written and verbal feedback on recruitment plans, focus group guides, preliminary data analysis, and all study policy briefs. In addition to the advisory board, key informant interviews with 28 DACA-eligible immigrants, advo-

cates, health care providers, and policymakers informed the research team about community outreach sites and barriers to research and health care engagement in the undocumented and DACA-eligible community.

The study team included two DACA-eligible interns hired through the "DREAM Summer Internship" program at the University of California Los Angeles Labor Center. Interns drew on their extended social networks within the undocumented community and their connections with local organizations to gain the trust of key players, such as leaders at immigrant legal aid sites and CBOs in the undocumented and DACA-eligible communities in northern and southern California. These efforts culminated in a robust participant recruitment plan driven by trusted peer referrals.

The research team, including the interns and two additional bilingual researchers, recruited participants in person at legal aid immigration clinics, college campuses, Latino- and immigrant-serving CBOs, churches, farmers markets, and parks. In-person recruitment occurred during general community events and DREAMer-targeted events such as legal aid clinics for DACA applicants and local DREAMer conferences. Board members, DREAMer interns, key informants, and social media sites assisted with the identification of these events. English and Spanish flyers outlining the study's purpose, inclusion criteria, and dedicated phone and email contacts were available at each community site for distribution. Community partners were wide ranging in their missions and engagement strategies, including those focused on education, labor, health care, legal aid, policy advocacy, and English as a second language. Most partnering organizations were located in Latino communities such as San Francisco's Mission District, the Fruitvale neighborhood in Oakland, and East Los Angeles. Figure 1 summarizes community engaged recruitment strategies.

The team solicited support from CBOs and student groups affiliated with DREAMers, which distributed recruitment materials through their email lists and social media pages (predominantly Facebook with some use of Twitter and Instagram). To prevent undue coercion and remain in compliance with our IRB recruitment and incentive plan, partnering organizations did not mandate study participation, provide additional incentives, nor were they informed of participants' identities. The study team also developed its own Facebook page with recruitment information, DREAMer-related news articles, DREAMer resources, and dissemination of our team's research findings. We shared the study's Facebook page with CBOs, student groups, and DREAMers.

The study's recruitment strategy and confidentiality policies were formulated through an iterative process with the IRB of the University of California San Francisco. The IRB expressed appropriate concern about the vulnerability of study participants, both because they might be in the United States without legal status and because we recruited them for participation owing to their current or prior illegal immigration activity. Owing to the sensitive nature of recruiting these participants, researchers worked with the IRB to develop a written screening tool to guide participants through the DACA program criteria, allowing participants to confirm or deny their DACA eligibility without forcing them to disclose their current immigration status (Appendix A). We invited participants to join the study if they were DACA-eligible, regardless of whether or not they had yet received DACA.

The research team also worked with the IRB to develop consent procedures to protect the safety and privacy of this vulnerable population. Although the IRB initially requested written informed consent, as is standard when conducting research with vulnerable participants, after discussing the increased risk of collecting unnecessary identifiers in this population the IRB agreed that, to protect participants' identities and alleviate concerns about disclosure of immigration status, verbal consent was preferable.

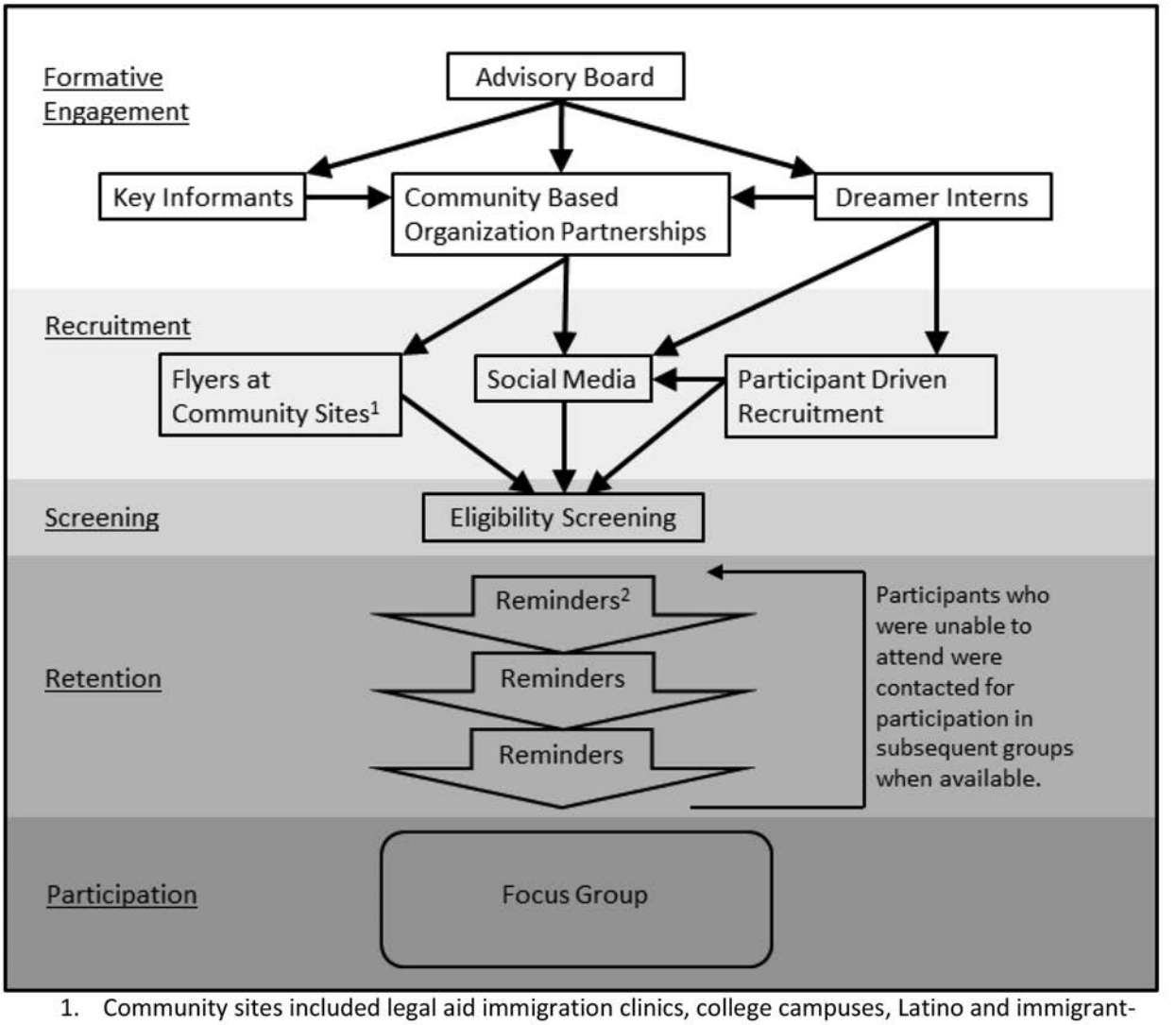
After initial eligibility screening onsite or by phone, participants provided their preferred mode of contact (email, texting, or phone), for reminders before their chosen focus group. DREAMer interns reminded participants about the focus group time and location 24 to 48 hours in advance. DREAMer interns made up to five attempts via texts, calls, or emails to verify or reschedule each participant's focus group attendance.

Focus groups took place in community-based settings that our board identified as engaged in advocacy and trusted within the undocumented population. CBOs providing space for the focus groups received a $200 honorarium. Each site was accessible via mass transit and focus groups occurred during evening hours to maximize the inclusion of working participants.

To provide additional support to the study participants, the DREAMer interns compiled resource guides with information about local, statewide, and national community agencies that deliver medical care, mental health care, and legal aid to the undocumented community. Resources were drawn from the board, key informant interviews, partnering CBOs, and the personal knowledge of study team members, particularly the DREAMer interns.

Before each focus group, participants completed an anonymous demographic and health questionnaire. Participants received a $20 discount store gift card, dinner, and the resource guide. Bilingual and bicultural moderators facilitated and recorded each 60- to 90-minute focus group. Discussion was primarily in English, although participants used Spanish intermittently.

The moderator's guide topics included health concerns, health care access, and strategies for maximizing health care outreach to undocumented youth. The guide was designed to begin with general discussions of health and move into more sensitive topics such as how documentation status affects mental health and community engagement. Based on feedback from one of the early focus group host sites, we



1. Community sites included legal aid immigration clinics, college campuses, Latino and immigrant-serving community based organizations, churches, farmers markets, and parks.
2. Up to 5 reminders were incorporated via texts, phone calls, and/or email according to each participant's preferred methods of contact.

Figure 1. Community-Engaged Participant Recruitment Strategies and Study Pathway

incorporated a closing exercise, known as *circulo* into the discussion guide. This tool, used among local DREAMer support groups, allowed participants to reflect on their experiences in the group, give feedback on the research process, and leave with a sense of closure regarding any difficult feelings that arose during the discussion. After professional transcription, three experienced qualitative researchers analyzed the focus groups using a modified grounded theory approach assisted by the program Atlas.ti.

We validated our findings at an in-person convening of the board, community partners, and a group of DACA-eligible immigrants. The research team also disseminated two study briefs summarizing these findings via our network of stakeholders, the project's Facebook page, and a policy briefing including community partners and DREAMers in the state capitol.

LESSONS LEARNED

Recruitment Challenges

The above methods culminated in the recruitment of 119 DACA-eligible immigrants, with 61 participants taking part in one of nine focus groups, representing a 55% retention rate (Table 2). Recruitment strategies were similar between those who attended and those who were lost to follow up. Among the "no-show" participants, frequently reported reasons for missing the focus group included competing demands for their time (work, school, and family obligations) and transportation issues. Two participants arrived for the focus group, but were unable to participate owing to lack of childcare. Given that participants cited family obligations as one of the most common reasons that they were unable to attend, onsite childcare would have likely improved our retention of some participants.

Successful Recruitment Strategies

With 42% of participants recruited through social media, Facebook was the most effective recruitment tool, including the study's Facebook page, pages of partnering CBOs, and reposting of study information by individual DREAMers. Although Facebook was the only social media account maintained by the study, participants reported discussing the study with peers on other sites including Instagram and Twitter. We recruited 39% of participants through CBOs. The most successful recruitment settings were legal clinics that assist immigrants with their DACA applications and local conferences for undocumented youth. Not surprisingly, DREAMers at these events were more willing to disclose their immigration status and seemed more open to hearing about opportunities to engage in research.

Peer-driven referrals yielded 36% of participants, most of whom heard about the study from an acquaintance or relative who had been recruited via other channels. Peer-driven referrals were bolstered by the engagement of the study's interns. These DREAMer team members were critical to building community engagement, overcoming participants' mistrust of research and academic institutions, and identifying high-yield recruitment settings and social media strategies. Flyers as a sole method of recruitment were the least effective, yielding 10%

Table 2. Characteristics of Focus Group Participants[5] ($N = 61$)

Characteristic	*n* (%)
Age in years, range	22.4 (18–30)
Female	36 (59)
Latino	61 (100)
Country of origin	
Mexico	53 (87)
Other	8 (13)
Activist for immigration reform	44 (72)
Single without children	54 (89)
Employment status	
Full time or part time	46 (76)
Self-employed	3 (5)
Unemployed	15 (25)
Income <139% federal poverty level	21 (43)

Table 3. Sources of Recruitment Reported by Participants*

Source	*n* (%)
Social media	26 (43)
Community-based organization	24 (39)
Research flyers	6 (10)
Peer-driven recruitment	22 (36)

*Some participants cited that they were recruited via multiple methods.

of participants. Of the participants who did respond to flyers, participants exclusively used email to contact the researchers, with no calls received to the dedicated phone line; this may have been related to difficulty coordinating calls during work hours or a generational preference for electronic contact given the relatively young age of DACA-eligibles. Owing to the close social networks in the undocumented community, participants often heard about the study through multiple recruitment channels, which contributed to the study's legitimacy and helped to create a sense of credibility and trust. Table 3 summarizes these data. Gender of participants did not vary by recruitment strategy. Unsurprisingly, participants who were more engaged in activism were more likely to hear about the study through peer or online activist communities.

Table 4. Research and Health Care Services Outreach Strategies Suggested by Focus Group Participants

Community settings
Immigrant groups or undocumented support groups
Schools and colleges, particularly with ESL classes
Health clinics
Churches
Health fairs
Community murals or public art projects
Bus stop ads
Media
Univision
Advertising during Telenovelas
YouTube – for advertising and instructional videos
Facebook
Instagram
Twitter
Government websites
Advocate Groups
Asian Students Promoting Immigrant Rights through Education (ASPIRE, http://aspireDREAMers.org/)
Central American Resource Center (CARECEN)
Coalition for Humane Immigrant Rights of Los Angeles (CHIRLA, httpwww.chirla.org/)
Dream Resource Center at UCLA (www.labor.ucla.edu/what-we-do/dream-resource-center/)
Educators for Fair Consideration (www.e4fc.org/)
National Council of La Raza (www.nclr.org/)
Poder (www.podersf.org/)

Proposed Engagement Strategies with Undocumented Populations

The focus group discussions included an opportunity for participants to suggest strategies for engaging the undocumented community in health programming. Many of their suggestions also have relevance for engaging the undocumented community in research. As noted, focus group participants suggested partnering with CBOs, including immigrant advocates, specific national and local advocacy groups, local clinics, churches, schools, and English as a second language programs (Table 4). One participant explained that information "has to come from a source that you trust because, otherwise it [is a] community that may be scared."

Participants suggested media outreach strategies targeted at different ages of undocumented community members. They proposed advertising during telenovelas and local Spanish language news programs to target older generations of immigrants. In contrast, they suggested using Facebook, Twitter, and Instagram to target adolescents and young adults. Although participants expressed wariness about disclosing their documentation status to health care or government officials, they identified government web sites as trusted sources of health information. Participants emphasized that one successful recruitment strategy would be to target family members of the intended audience. "Our parents are always on the lookout for anything that can benefit us," one participant explained.

The Community's Call for Additional Research

Study participants were strong advocates for additional research to investigate the health needs and health care experiences of the undocumented community. Respondents viewed participation in this study as an opportunity to use research as a form of advocacy to improve immigrant health. "It's very empowering to know that you guys are fighting for us too, even in research," one participant explained. Participants reported that the undocumented community has limited social capital and political force. One participant expressed, "there isn't no empathy for this population, you know. We're left out of the discourse of a lot of things." Another elaborated: "We don't have much of a political voice. And I mean, it's people who haven't experienced what we've experienced deciding what's best for us."

As part of the closing *circulo*, participants expressed a desire to know more about how the study results were going to be used. Participants identified research as a viable tool to ameliorate their sense of shared disadvantage, expressing a hope that research might influence public policy. Others saw research as an opportunity to bring a more human perspective to immigration policy discussions: "It's always like 2.1 million undocumented youth in the United States. And it's like, no. Like I'm an individual. I'm a human being. Give me some dignity and respect . . . you're putting a face to it and a story."

Overall, participants expressed satisfaction with their involvement in this study and a desire to see further engagement of the undocumented community in health and public policy research.

DISCUSSION

This paper is the first to describe successful research engagement strategies with DACA-eligible immigrants. Although prior research, including our findings from these focus groups, suggest that undocumented populations are hesitant to disclose their status to government agencies and health care providers owing to fear of deportation,[15,16,23,24,29] participants in this study expressed enthusiasm about engagement in research as undocumented immigrants. This support likely reflects both the politically engaged nature of DREAMers as well as the research team's substantial efforts to engage the community in creating a comfortable and nonthreatening research experience. These efforts included not requiring participants to verify their current immigration status, eliminating the requirement for written consent, reassuring participants of confidentiality, and informing participants that their stories might help others who are in their same position. Multiple reinforcing recruitment strategies also built a sense of trust in the community, particularly as peer referrals played an important role in establishing credibility.

Despite misconceptions that minorities are unwilling to enroll in research, these findings support previous work that demonstrates that minority populations are willing to engage in research under appropriate circumstances and with assurance of confidentiality.[30] Participants in this study indicated that their comfort engaging in research and health programming was largely dependent on the type of outreach strategy used. Supporting the limited research with other particularly vulnerable Latino populations including undocumented women, drug users, patients with human immunodeficiency virus, and children,[9,20,21,25,31] participants confirmed that they preferred engagement through trusted advocacy groups and CBOs. They emphasized building on their close-knit social networks and using participant-driven recruitment.[32]

Participants also identified contact with family members within the undocumented community as a possible outreach strategy, suggesting age-appropriate Spanish-language media channels to reach adult family members who might refer other family members to research participation or health care. Although this is similar to social marketing techniques used with other vulnerable populations,[32] participants in this study specifically suggested the greater use of social media web sites to reach undocumented young people. This strategy supports a growing body of literature on using social media for recruitment of vulnerable populations.[33–36] In addition, participants in this study were successfully recruited using interactive engagement with technology through social media, email, and texting, suggesting that the previous technological divide between Latino populations and the general public may be rapidly changing within undocumented communities.[37]

Overall, this study demonstrated that it is possible to partner with CBOs and undocumented community members to successfully conduct research to learn about their health concerns and health care access. Our experience in this study highlights the importance of community partnership and the interest of the undocumented community in using research to give voice to their health concerns.

LIMITATIONS

This paper focuses on the recruitment and engagement of DACA-eligible youth, a subgroup of the undocumented community, which is by definition relatively young and educated. This study focused on Latino participants, most of whom emigrated from Mexico. Although this is consistent with national trends, it may limit the study's generalizability to immigrants from other countries. In addition, the majority of the research participants also self-identified as engaged in immigrant-related activism. This is likely related to our recruitment strategy of partnering with advocacy organizations, but it may also be related to increased political and community engagement emerging because of DACA and immigration reform efforts.

It remains to be seen if similar recruitment and engagement strategies will be effective in other undocumented populations such as those who are older or who are not yet benefiting from community engagement through policy changes like DACA. Despite the highly engaged nature of our participants, the research team and community partners' best efforts yielded only a 55% retention of those who screened as eligible for the study. Although we know little about those who did not participate in this study, because recruitment strategies did not vary between the groups, improving participant retention further might require additional creative solutions such as recruiting in new settings (eg, job sites), providing childcare, or increasing incentives to complete with the other demands for participants' time.

CONCLUSIONS

Despite the insular nature of the undocumented community, trained to remain below the radar of government and authoritative bodies, the immigrants in this study were willing to participate in research as a means of advocating for health care and public policy changes. As investigators complete more studies with undocumented participants and changes in federal and state policy emerge, it will be increasingly necessary for researchers to build partnerships with the community, continue sharing recruitment best practices, and engage in the sharing of research findings with immigrants, as well as with policy stakeholders. Further research that is rooted in the inherent cultural humility of community-based participatory research will allow investigators to identify additional best practices, particularly important as challenges in recruiting undocumented participants are likely to be magnified in older, less engaged, and rural undocumented subpopulations, requiring further engagement with trusted CBOs, family members, and diverse media for penetration into these harder to reach enclaves. Future studies can also strive to achieve additional tenets of community-based participatory research, including involving community members in data analysis, manuscript development, and working with communities to design interventions to improve their health and health care access.

Appendix A: Abbreviated Participant Screening Script Used by Research Assistants

We are interested in the experiences of young people who are eligible for DACA, or the Deferred Action for Childhood Arrivals program. I am going to describe the eligibility criteria for the DACA program and then ask you whether you meet all of these criteria. (Recruiter will give potential participant these criteria on a piece of paper, will read the criteria out loud, and answer any questions about the criteria.)

You are eligible to apply for DACA if you:

- were less than 31 years old as of June 15th, 2012,
- immigrated to the United States at younger than 16 years old,
- entered without paperwork before June 15, 2012, or your lawful immigration status expired as of June 15, 2012 or you have received permission to stay in the United States through the DACA program
- have lived in the US for at least five years,
- have no criminal record, and
- you are currently in school (guidelines listed below), have graduated or obtained a certificate of completion from high school, have obtained a general education development (GED) certificate, or are an honorably discharged veteran of the Coast Guard or Armed Forces of the United States.

Do you meet these DACA eligibility criteria?

[ ] If do not meet the DACA eligibility criteria then STOP ●—NOT ELIGIBLE.
[ ] If do meet these DACA eligibility criteria then continue ➔

How old are you?

[ ] If younger than 18 or older than 31 then STOP ●—NOT ELIGIBLE.
[ ] If 18 to 31 years old then continue ➔

What country were you born in?

[ ] If not from Latin America (listed below) then STOP ●—NOT ELIGIBLE.
[ ] If from Latin America (listed below) then continue ➔

Are you comfortable participating in a group discussion in English?

[ ] If no then STOP ●—NOT ELIGIBLE.
[ ] If yes then continue ➔ PARTICIPANT IS ELIGIBLE FOR THE STUDY

Appendix continues

What is your gender? _____

Are you currently a college student? _____

If yes, are you a student at a University of California campus? _____

Do you currently have health insurance? _____

Latin American Countries

Argentina	Colombia	El Salvador	Panama
Belize	Costa Rica	Guatemala	Paraguay
Bolivia	Cuba	Honduras	Peru
Brazil	Dominican Republic	Mexico	Uruguay
Chile	Ecuador	Nicaragua	Venezuela

[ ] other – If the participant describes themselves as Latin American but their country is not listed above, talk to local study coordinator.

"Currently in school" guidelines

- a public or private elementary school, junior high or middle school, high school, or secondary school
- an education, literacy, or career training program (including vocational training) that is designed to lead to placement in postsecondary education, job training, or employment and where you are working toward such placement
- an education program assisting students either in obtaining a regular high school diploma or its recognized equivalent under state law (including a certificate of completion, certificate of attendance, or alternate award), or in passing a General Educational Development (GED) exam or other equivalent state-authorized exam

DACA Eligibility Handout

You are eligible to apply for DACA if you:

- were less than 31 years old as of June 15th, 2012,
- immigrated to the United States at younger than 16 years old,
- entered without paperwork before June 15, 2012, or your lawful immigration status expired as of June 15, 2012 or you have received permission to stay in the United States through the DACA program
- have lived in the US for at least five years,
- have no criminal record, and
- you are currently in school (guidelines listed below), have graduated or obtained a certificate of completion from high school, have obtained a general education development (GED) certificate, or are an honorably discharged veteran of the Coast Guard or Armed Forces of the United States.

Do you meet these DACA eligibility criteria?

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