

## **Establishing a national engagement strategy for recruiting Asian Americans and other minorities into biomedical research**

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**ABSTRACT:**

**Background:** The All of Us Research Program (AoURP) seeks to advance precision medicine and reduce health disparities by recruiting people in demographic categories that are underrepresented in biomedical research. Asian Americans, Native Hawaiians and Pacific Islanders (AANHPI) are the most understudied of all racial/ethnic groups in the US. We propose a national engagement strategy for the recruitment of AANHPI into biomedical research using a community-based participatory research (CBPR) approach.

**Methods:** We partnered with Asian serving community base organizations (CBOs) across the US to increase education and awareness and developed a culturally and linguistically tailored approach for the engagement of AANHPIs into AoURP.

**Results:** In the first year, our national engagement strategy reached over 35,000 AANHPIs through promotional events and educational sessions.

**Conclusions:** Our success is a result of our equal and mutually beneficial partnership with CBOs who have access to rich, local knowledge and hold a unique role within the community.

**KEYWORDS:** Asian Americans; Native Hawaiians; Pacific Islanders, Community-Based Participatory Research, Biomedical Research, Health, Community Engagement

## Introduction

The All of Us Research Program (AoURP) is a longitudinal cohort study funded by the National Institutes of Health (NIH). This program seeks to advance precision medicine and improve health through the enrollment of at least one million diverse individuals living in the United States (US).<sup>1-3</sup> One of the central goals of the AoURP is to recruit people in demographic categories that have been and continue to be underrepresented in biomedical research, including racial/ethnic minorities.<sup>2</sup> In fact, Asian Americans, Native Hawaiians and Pacific Islanders (AANHPI) are the most understudied of all racial/ethnic minority groups in the US, overlooked in both national health surveys and clinical trials.<sup>4-8</sup>

Barriers to enrollment and recruitment of AANHPI populations in clinical research have been previously documented.<sup>4,5,9,10</sup> These barriers may include mistrust of researchers and health providers and lack of knowledge with regards to the significance of clinical trials to the health of communities.<sup>5,11</sup> Moreover, the complex consent forms and procedures and limited availability of Asian languages, prevent many AANHPIs from participating in health surveys, particularly those who have low English proficiency.<sup>4,5,9,10,12</sup>

In response, there has been considerable research that aims to develop strategies to reduce barriers for minority recruitment in clinical research.<sup>4,13</sup> Previous systematic reviews examining recruitment strategies for underrepresented populations conclude that community engagement approaches may effectively promote recruitment and retention.<sup>14-17</sup> Studies have shown that successful local recruitment strategies for engagement of AANHPI populations in clinical trials may include partnerships between community-based AANHPI providers and larger medical centers or research institutions.<sup>4,5,18-20</sup>

Community based participatory research (CBPR) approaches have also been used to engage and recruit AANHPI in health research.<sup>20</sup> Core values of this approach include partnerships between community stakeholders and researchers to establish an equitable power distribution and mutual trust.<sup>7,20</sup> However, to date, there are no studies that have aimed to recruit a national sample of AANHPI using a CBPR approach. In this study, we describe a national engagement strategy for the recruitment of AANHPI into biomedical research. Our strategy was guided by three key CBPR principles: 1) community as a unit of identity 2) engaging in co-learning and capacity building 3) facilitating collaborative, equitable partnerships in all research phases and 4) building on strength and resources within the community. In the following sections we describe the steps taken to develop our national engagement strategy using a CBPR framework and the lessons learned in the first year of our program

### **Increasing recruitment of AANHPI in AoURP through a CBPR approach**

The AoURP was launched in May 2018 and as of May 2020, the program had enrolled over 345,000 participants, with the goal of recruiting 1 million individuals.<sup>3</sup> Participants can enroll online through the AoURP website or on-site through health provider organizations (HPO) such as regional medical centers and federally qualified health centers associated with the AoURP consumption.<sup>21</sup> Once consented, participants complete an online health surveys, physical measurements, provide permission for access to electronic health records (EHR) and provide blood or saliva biospecimens. Currently, the AoURP surveys and consent forms are not available in any Asian language (only available in English and Spanish), which may prevent many AANHPIs from participating, particularly those with low English proficiency. Therefore, to encourage the enrollment of underrepresented populations, the NIH funded a national network of community engagement partners to educate, motivate and facilitate enrollment of diverse

populations.<sup>1,2</sup> In 2018, the Asian Health Collation (AHC) was selected as a national community engagement partner to increase engagement of AANHPIs in AoURP. The AHC is a non-profit, capacity building community-based organization (CBO) focused on improving the health and well-being of Asian Americans through advocacy, technical assistance, cultural competency, and education.

### **Establishing a network of national partners that serve AANHPI communities**

We developed a national engagement strategy that leverages Asian serving CBOs, health care providers and national partners (AoURP consumption and NIH) to facilitate the recruitment of AANHPIs using a culturally tailored approach.

From the initial conceptualization of our national engagement strategy, we assembled the National Asian Engagement and Recruitment Core (ARC), a network of organizations serving AANHPI population across the US to co-create processes to engage our target communities.

The selection of the ARC partner organizations was based on meeting at least two of the three criteria: 1) close proximity to NIH-designated HPOs, 2) close proximity to large concentrations of AANHPI populations and/or 3) the ability of the organization to reach AANHPI populations locally and/or nationally. To select organizations for the ARC, we initially identified geographical areas with large concentrations of AANHPI populations defined by the US Census, and that were in close proximity to the NIH-designated HPOs (Figure 1). Using the map on Figure 1, we selected four target regions across the US (i.e., East Coast, Midwest, South and Southwest/West coast) and determined the specific number of CBOs per region based on AANHPI population density, to ensure diverse representation of AANHPI populations. We used the Internal Revenue Service (IRS) database of tax-exempt organizations across the US to

generate a list of nonprofit Asian serving organizations (N=1076) and filtered by those CBOs (N=456) located in the target regions (i.e., East Coast, Midwest, South and Southwest/West coast). We emailed an introductory letter and our application to the 456 identified CBOs and received and reviewed 12 applications.

### **Selection process**

All applicants completed an online application describing their organizations' capacity, population served, experience in engagement, type of services provided and experience with research. To ensure a rigorous selection process, we chose a panel of five experts in community outreach and behavioral science to weight 18 organizational capacity items (e.g., experience in community engagement with AANHPIs, availability of staff for the project) using the Delphi method<sup>22</sup> to make the final selection of partners (Figure 1). Six organizations were selected to join the ARC. We also invited two Asian serving national organizations to join the ARC, that we had collaborated with previously.

The ARC membership included the executive director and two to three organizational champions (i.e., individuals who possess the experience, enthusiasm and skills to encourage and support their communities to engage in health promotion activities)<sup>23</sup> from each organization. Table 1 describes the characteristics of the ARC members (six CBOs and two national organizations). The CBO partner organizations selected for the ARC collectively served between 2,500 and 20,000 AANHPIs from 22 nationalities in 12 languages, each year, while the national organizations had over 140 chapters across the US. In general, over 40% of the AANHPIs served by these organizations reported that English was not their primary language.

### **The ARC strategic approach: using CBPR principles to establish engagement strategies**

Over the course of the first year, the ARC met face-to-face on two occasions and once every month through a virtual meeting platform, to ensure equal participation. We also held meetings at each partner organization site to immerse the group in local learning and community engagement and better understand our partners' organizational capacity (i.e., staffing, reach in the community). Through these meetings, the ARC established three priorities necessary to increase capacity for recruiting AANHPI into AoURP that aligned with the CBPR framework (Table 2): increase education and awareness, build capacity of ARC partners and HPOs to interact and develop collaboration and enhance a culturally and linguistically tailored approach to engagement. To achieve these priorities, we piloted an education and outreach program around AoURP based on the community health worker (champion) model. To this end, AANHPI serving champions who have access to rich, local knowledge and are bilingual, bicultural members of the target community, were trained on AoURP enrollment procedures and protocols to provide context on the experiential process and to share insights and feedback for designing education and outreach activities that be culturally appropriate for AANHPI communities. Specifically, the champions reviewed all established AoURP marketing and communication materials (i.e., infographics, general flyers and program fact sheets) and the online enrollment process (i.e., consent forms).

During our face-to face and web based meetings, the thematic concerns and considerations identified by the ARC partners were discussed. These themes were used to develop relevant culturally tailored messaging to engage AANHPI populations around AoURP. The ARC champions were encouraged to navigate the actual AoURP online enrollment process (ARC champions were not required to submit their information and provide EHR consent unless they were interested in enrolling). Through this experiential process, the ARC champions' first-

hand experience created an additional opportunity for real world feedback related to barriers their community may encountered during the enrollment process. Based on these experiences and feedback and in collaboration with the ARC, we develop key recommendations to address these identified barriers in order to improve the overall engagement and recruitment of AANHPIs in AoURP (Table 3).

The recommendations to barriers to recruitment and engagement were shared with the NIH and were used to inform the development of AoURP national engagement strategy for AANHPIs. The ARC identified three objectives to guide the national engagement strategy: 1) co-create a curriculum to train a cohort of ARC Champions around AoURP, 2) facilitate culturally and linguistically tailored promotion and engagement about AoURP, and 3) build trust to develop a shared understanding about clinical trial participation and enrollment among the ARC members and HPO partners.

### **Co-create a curriculum to train a cohort of ARC champions around AoURP**

In collaboration with the ARC including the thematic barriers identified by the champions, presentations from subject matter experts and the AoURP recruitment protocols, we created a culturally and linguistically tailored curriculum to improve the outreach and education capacity of the ARC champions. This training involved a sequence of six online modules focused on the fundamentals of the AoURP engagement and enrollment process. The models covered the following topics: 1) Culturally Tailored Marketing & Communications 2) Community Engagement & Education on AoURP 3) AoURP Online Enrollment Process 4) Enrollment Processes via HPOs sites 5) AoURP Genomics & Return of Results and 6) AoURP Data Browser. Each online module lasted 60 minutes and the trainings took place over a five week period. In the first year of the program, 18 champions were trained. The curriculum was



evaluated using pre- and post- surveys to assess knowledge related to effective engagement (e.g. “List your top three approaches in promoting AoURP events to your community members”) and to assess confidence in explaining the AoURP enrollment process (e.g., “At this point in the ARC program, how confident are you in explaining the All of Us enrollment process to your community members?”) using a 5-point Likert scale. The majority of ARC champions improved their confidence (i.e., felt confident or very confident) to motivate and educate their community around biomedical research.

The ARC also created a training curriculum to educate health providers organizations responsible for enrollment to the AoURP, to be sensitive and culturally responsive when engaging and recruiting AANHPIs around AoURP. Although we asked the health providers to complete a pre and post-test to evaluate the effectiveness of this curriculum, the data analysis is ongoing.

### **Deliver culturally tailored promotion and engagement around AoURP**

The ARC identified the importance of culturally and linguistically tailored messaging to engage and motivate AANHPI communities to participate in AoURP. To this end, the ARC developed culturally and linguistically tailor online messaging (i.e., Facebook, Twitter, and WeChat), and marketing and communication materials (i.e., bilingual infographics, general flyers and program fact sheets) to improve engagement of AANHPI communities in the program. The marketing and communication materials were developed in three languages (i.e., Korean, simplified Chinese and Vietnamese) with appropriate ethnic specific images that matched the targeted ethnic subgroup. Prior to dissemination, all promotional materials were translated by NIH using their language translation guidelines and were subsequently reviewed for language and cultural relevance by ARC community partners. These languages were chosen based on the

demographics of AoURP participants. However, the ARC also identified the need to translate promotional materials into many additional languages (e.g., Hindi) in order to engage a more diverse groups of AANHPIs to the program.

### **Build trust and develop a shared understanding about clinical trial participation**

In order to successfully recruit AANHPI participants to AoURP, it is crucial that the HPOs, responsible for recruitment and enrollment, are trusted by the community. To that end, the AHC created bidirectional partnerships and training for HPOs and ARC members in regions with high density of AANHPI populations. HPOs were trained on culturally sensitive ways to engage with AANHPI populations while our ARC partners learned about the HPOs' enrollment process. These bidirectional collaborations catalyzed new relationships and trust among participants. For instance, a key collaboration involved one ARC partner CBO and a HPO, who strategically collaborated to host a two-day engagement/enrollment event. On the first day, the CBO educated community members about AOURP and facilitated online enrollments. This allowed the HPO to collect physical measurements and blood biospecimens on the second day. Fifteen participants were successfully enrolled during this event. Through this partnership, we learned that it may be more effective and efficient to enroll participants right after engagement and education efforts.

### **Results from the national engagement strategy**

In our first year, our multipronged national engagement strategy reached over 35,000 AANHPI through promotional events and educational sessions (Table 4). The recruitment of AANHPI participants who enrolled (registered and completed consent forms) into the program between October 2018 (when the AHC join AoURP as a national engagement partner) and October 2019 increased by 151% among AANHPI. Although we do not have direct data to correlate the increase in recruitment with our engagement and education strategies, the

significant increase in AANHPI participants who enrolled in the program during this time may have been significantly influenced by our national engagement strategies.

The success in AANHPI outreach was facilitated by our culturally and linguistically tailored engagement strategies that functioned to overcome barriers to engagement and recruitment. First, our engagement/outreach efforts were delivered by bilingual and bicultural community champions, who were trusted members of the AANHPI communities they served. Second, in collaboration with the ARC we established best engagement/outreach practices for recruiting AANHPI in clinical research, including identifying strategic venues for AANHPI outreach. Finally, in collaboration with the NIH, the ARC developed and disseminated culturally and linguistically tailored online messaging and promotional materials to help engage AANHPI communities.

Beyond the culturally and linguistically tailored educational and promotional material created by the ARC, our partners used different strategies to successfully reach and engage AANHPI communities from diverse ethnic backgrounds (e.g. Korean, Chinese, Cambodian, Vietnamese, South Asian and Lao). For instance, one ARC partner found that Korean churches are an important venue when engaging Korean communities while Vietnamese communities can be successfully reached at Vietnamese beauty schools. Social media platforms which were used to provide culturally-tailored outreach, differ among diverse AANHPI groups. For example, while WhatsApp is popular among Asian Indians, mainland Chinese use WeChat and Chinese from Taiwan and Japanese communities use Line messaging app. Our ARC partners also found that effective culturally engagement strategies differ by age group. For instance, our ARC partners found that ethnic festivals and new year events are ideal venues to promote the AoURP among older adults who usually attend traditional events. AANHPI older adults can also be

successfully reached at local ethnic based senior homes, community-based agencies, and cultural group meetings.

### **Practical Lessons Learned**

The use of a CBPR approach to overcome barriers to engagement and recruitment of AANHPI in clinical research, have yield positive results. Our success is a result of our partnership with CBOs who have access to rich, local knowledge and hold a unique role within the community. This is particularly important when engaging AANHPI communities, who are culturally and linguistically diverse. Below we describe three important lessons learned from our partnership with these organizations through an existing CBPR framework.

#### **Lesson 1: There is a need for equal partnership**

We attribute the success of our national engagement strategy to an equal and mutually beneficial partnership (between AHC and the ARC), that facilitated the development of several tools and resources aimed at educating, motivating and engaging AANHPIs in biomedical research. From the conception of the ARC, we ensure that all CBO partners had an equal role in establishing project objectives, developing educational and promotional activities and disseminating results. For instance, our ARC partners were instrumental in identifying the barriers to recruitment and engagement of AANHPI communities into precision medicine, described in this manuscript. This information was gathered in the first year of the program through individual meetings (between AHC and ARC partners), group discussions and reporting feedback. The equitable nature of the partnership was also reflected in the way we conducted our meetings. Before each monthly meeting, we asked our ARC partners to provide information about barriers and gaps they had in the training (e.g., more information on genetics”) or

engagement of AANHPI communities in AoURP, so that we could better served their needs. We used this feedback to create meeting agendas that were tailored to meet our partners' needs.

***Lesson 2: Co-learning process are necessary to improve engagement of AANHPI communities into precision medicine***

Through a “shared learning process” adopted in this program, we were able to identify important barriers to engagement and recruitment of AANHPI communities in precision medicine. For instance, our ARC partners mentioned that some AANHPI communities (i.e., Chinese and Vietnamese) have different concepts of healthcare that may pose cultural barrier to recruitment into precision medicine. Some AANHPI groups believe in “natural healing” through food and herbs, so medical research and precision medicine in particular, are not a priority for them.

Additionally, and consistent with the literature,<sup>24</sup> our ARC partners expressed that AANHPIs have a general distrust of western medical care and do not feel comfortable attending health care facilities. This is an important barrier to recruitment of AANHPIs into precision medicine as face-to-face recruitment is mainly delivered through HPOs associated with the AoURP consumption. Health professionals do not always know the best strategies to engage AANHPIs into medical research and use of medical jargon can increase AANHPIs reluctance to participate in the program (particularly those with low English proficiency and older adults). This sentiment was reflected by one our ARC partner:

*“Education about AoURP should be described in informal terms, such as discussion or dinner table conversations.”*

Therefore, an important deliverable of this program was to create educational materials to train HPOs on culturally sensitive ways to engage with AANHPI populations.

### **Lesson 3: Flexibility is paramount**

CBPR requires a great deal of flexibility between community stakeholders and researchers and it is therefore important to acknowledge unforeseen factors that may occur in the process of shared partnership in research and practice<sup>25-27</sup>. For instance, CBOs and researchers may have conflicting agendas, misaligned outcomes of interest and timelines<sup>27</sup>. While researchers need to be responsive to the goals, objectives and deliverables outlined in their funding, it is also important for them to listen to their partners and advocate for the particular needs of the community. For instance, in this program we uncovered several barriers to engagement and recruitment of AANHPI communities such as limited information about AoURP in AANHPI languages. Although translating promotional material to different AANHPI languages was not a program deliverable, our ARC partners voiced the importance of creating these promotional assets to successfully engage AANHPIs into AoURP. In the first years of the program, we were able to develop three promotional assets in three AANHPI languages. The ARC also identified and provided recommendations for additional languages that still need to be addressed by the AoURP consortium and for the translation of informed consents on the AoURP website to languages that are relevant to this population. This is an ongoing process.

### **Lesson 4: Building capacity is important**

Building capacity within communities is a core element in CBPR. However, small CBOs located in low income ethnic communities, struggle to secure adequate funding for programs and staff<sup>28</sup>. This has been previously documented as the *capacity paradox*, where small CBOs with established connections to the community are considered to be too small or to not have the

adequate capacity to support a multi-year grant<sup>28</sup>. When developing the ARC, the AHC ended this *capacity paradox* by including partners from ‘small capacity’ CBOs who were able to adequately reach high numbers of AANHPI communities from diverse ethnic and socioeconomic background. For example, one of our CBO partners was able to successfully engage a significant number of hard -to -reach AANHPIs but had limited staff. Even with additional funding provided by this program, it was not feasible for this CBO to hire additional staff members to provide engagement around AoURP. Therefore, we worked with them so that they could incorporate AoURP engagement strategies into their existing programs and simultaneously helped them build capacity in this way. Additionally, the funding from this program helped another ARC partner support an additional staff member. With the support of an additional staff member, this CBO was not only able to promote the AoURP among their AANHPI communities, but they were also able to expand their culturally adaptive health programming into other areas.

## **Conclusions**

This manuscript describes lessons learned from the first year of our program. Our national engagement strategy is a replicable model for initiatives who aim to recruit a national cohort of AANHPI in clinical research. Using principles of CBPR, we were able to co-create a strategic approach (i.e., culturally tailored curriculum and promotional assets) to reach over 35,000 AANHPI individuals through multimodal messaging, established broad and trusting partnerships with HPOs, the NIH and communities and witnessed an 151% increase in AANHPI enrollment during our first year. While we highlight important lessons learned from the development of our national engagement strategy, our ARC partners used different strategies to successfully reached and engaged AANHPI communities from diverse ethnic backgrounds (e.g., Korean, Chinese,

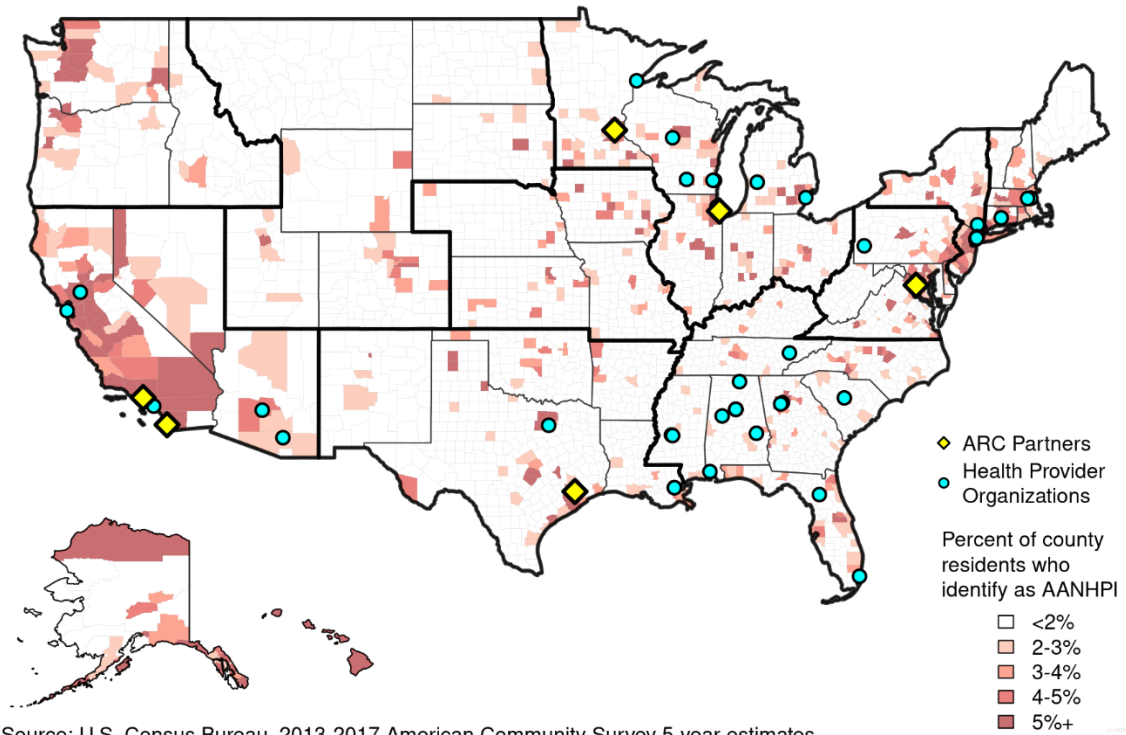
Cambodian, Vietnamese, South Asian and Lao). Although some of these specific engagement strategies are described in this manuscript, in future publications we aim to expand on the differences in engagement and recruitment of AANHPIs from diverse ethnic backgrounds into precision medicine. In the subsequent years of this program we will continue to build on our culturally relevant strategies to fully engage our AANHPI communities by expanding our ARC partnerships to other geographical regions with high prevalence of AANHPI populations. Ultimately, we want to ensure that our AANHPI communities benefit fully from participation in this groundbreaking AoURP study.



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**Table 1. Selected characteristics of ARC partners**

<b>ARC Partners</b>	<b>Geographical location</b>	<b>Services provided</b>	<b>Asian communities served</b>	<b>Languages served</b>
<b>Community based organizations (CBOs)</b>				
<b>CBO1</b>	Houston, TX	Cancer support and screening, health care navigation	Chinese and Taiwanese	Mandarin, Vietnamese
<b>CBO2</b>	Minneapolis, MN	Multimedia education and production, community organizing	Asian Indian, Bhutanese, Cambodian, Chinese, Taiwanese, Filipino, Hmong, Japanese, Korean, Laotian, Mongolian, Sri Lankan, Thai, Vietnamese, Native Hawaiian or other Pacific Islander	Cantonese, Korean, Lao, Mandarin, Thai, Vietnamese
<b>CBO3</b>	Los Angeles, CA	Education and recruitment of potential bone marrow donors for patients with leukemia and other blood diseases	Asian Indian, Cambodian, Chamorro, Chinese, Taiwanese, Filipino, Guamanian, Hawaiian, Japanese, Korean, Samoan, Tongan, Thai, Vietnamese	Cantonese, Hindi, Japanese, Korean, Mandarin, Tagalog, Thai, Vietnamese
<b>CBO4</b>	Chicago, IL	Immigration and social services	Asian Indian, Bangladeshi, Nepalese, Pakistani, Sri Lankan	Bengali, Gujarathi, Hindi, Urdu
<b>CBO5</b>	San Diego, CA	Healthcare, health education and access to healthy food	Burmese, Chinese, Taiwanese, Filipino, Hmong, Korean, Vietnamese	Mandarin, Tagalog, Vietnamese
<b>CBO6</b>	Annandale, VA	Immigration and social services	Chinese, Taiwanese, Korean	Cantonese, Korean, Mandarin
<b>National AANHPI serving organizations (NSOs)</b>				

<b>NSO1</b>	Over 108 chapters throughout the U.S.	Services for medical and biomedical AANHPI students	Asian Indian, Bangladeshi, Bhutanese, Burmese, Cambodian, Chinese (including Taiwanese), Filipino, Guamanian, Hawaiian, Hmong, Indonesian, Japanese, Korean, Laotian, Malaysian, Mongolian, Nepalese, Pakistani, Samoan, Sri Lankan, Tongan, Thai, Vietnamese	Mainly use English for events, but have educational materials in various languages.
<b>NSO2</b>	32 chapters throughout the US	Services for patients with hepatitis B virus worldwide	Asian Indian, Bangladeshi, Bhutanese, Burmese, Cambodian, Chamorro, Chinese, Taiwanese, Filipino, Guamanian, Hawaiian, Hmong, Indonesian, Japanese, Korean, Laotian, Malaysian, Nepalese, Okinawan, Pakistani, Samoan, Sri Lankan, Tongan, Thai, Vietnamese, Chuukese, Marshallese	Mainly use English for events, but have educational materials in various languages.

**Table 2. Initial strategies for engagement and recruitment of AANHPIs into precision medicine using a community –based participatory research approach**

<b>CBPR Principles</b>	<b>Strategy</b>	<b>Description of the process</b>
Community as a unit of identity	Create a strong working relationship among ARC members characterized by trust, cooperation and respect	<ul style="list-style-type: none"> <li>• Face to face and virtual meetings among ARC champions and the AHC to stablish priorities to increase engagement and enrollment of AANHPI communities</li> </ul>
Engaging in Co-learning and capacity Building	Jointly develop educational material to train AANHPI serving champions around AoURP	<ul style="list-style-type: none"> <li>• The ARC champions learn about precision medicine.</li> <li>• The Arc champions went through AoURP online enrollment process and provided feedback and recommendations about how to make enrollment more accessible to AANHPI communities.</li> </ul>
	Co-created educational material meant to effectively engage AANHPI communities in precision medicine	<ul style="list-style-type: none"> <li>• The ARC identified strategic community venues and tools, as well as develop a variety of best practices for outreach and promotion.</li> </ul>
	Co-created and delivered culturally tailored AoURP promotion and engagement	<ul style="list-style-type: none"> <li>• The ARC identified effective value proposition approaches that may be appealing for AANHPIs and develop culturally sensitive messaging.</li> </ul>
Facilitates collaborative equitable partnerships in all research phases	Promote a sense of respect for all partner’s time, role and unique experience delivering health education and engaging diverse AANHPI communities	<ul style="list-style-type: none"> <li>• From the conception of the ARC we ensure that all CBO partners had an equal role in establishing project objectives, developing educational and promotional activities and disseminating results.</li> <li>• The AHC and AR partners also negotiated a fair distribution of grants funds.</li> </ul>
Builds on strength and resources within the community	Built a network of relationships among ARC members and health provider organizations responsible for AoURP enrollment	<ul style="list-style-type: none"> <li>• Facilitate a bi-directional partnership between health providers and ARC members where the ARC learned about the enrollment process and health providers learn about</li> </ul>

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effective and cultural appropriate ways to engage AANHPI communities.

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**Table 3. Key barriers to engagement and recruitment of ANHPIs in clinical research and recommendations to overcome these barriers.**

<b>Key issues</b>	<b>Barriers among AANHPI</b>	<b>Recommendations</b>
<b>Data privacy and distrust of the government</b>	<p>Despite the NIH’s robust privacy protection measures, many AANHPI communities have been hesitant of disclosing medial information to government programs like AoURP. Community members fear that their medical information as they are hesitant that their information will be misused by researchers.</p> <p>Particularly due to the present political climate, AANHPI community members who are undocumented or with expired documentation are fearful that this information will be shared with government officials.</p>	<ul style="list-style-type: none"> <li>• Promotional assets used for community outreach should include an explicit statement that ensures identifiable data will not be shared with any governmental agencies.</li> <li>• Organizations within the AoURP Consortium that conduct community engagement should establish trust with AANHPIs through local CBOs that have already gained their trust.</li> <li>•</li> </ul>
<b>Technology access</b>	<p>A large number of AANHPI community members lack an email address and/or a mobile phone number, as well as access to a computer and the Internet.</p> <p>Web-based surveys are a significant barrier to community members with low technology literacy such as older adults who find it difficult to navigate websites and online platforms.</p>	<p>NIH needs to identify alternative forms of enrollment to address this barrier.</p>
<b>Difficulty traveling to HPOs sites</b>	<p>HPO sites are not always located near an ARC partner, and it may be difficult for some AANHPI community members, particularly those who have low socioeconomic status(SES) to travel to these locations for physical measurements and biospecimens.</p>	<ul style="list-style-type: none"> <li>• The NIH should continue expanding HPO sites, especially near low SES ethnic neighborhoods.</li> <li>• The NIH should explore the possibility of having local health care clinics/physicians collect physical measurements and biospecimens.</li> </ul>
<b>Language Access</b>	<p>There is a lack of promotional assets translated into high-need Asian languages. Currently promotional assets have been translated to Korean, Simplified Chinese and Vietnamese.</p>	<p>To accurately represent the diverse group of AANHPIs, particularly those with low English proficiency, promotional assets and online messaging needs to be translated to</p>



		other languages (i.e., Hindi and traditional Chinese).
	The enrollment process is only available in English and Spanish. This may be discouraging to AANHPI communities and may decrease their interest in the program.	The online enrollment process needs to be translated to languages relevant to AANHPI communities.
<b>Cultural relevance</b>	<p>AoURP enrollment forms and health survey lack cultural relevance for AANHPI communities</p> <p>Some AANHPIs such as Cambodians may be hesitant to enroll in AoURP as culturally they are reluctant to give blood samples</p>	<p>Life style survey questions such as physical activity may be more inclusive if they include examples that are more relevant to AANHPI (e.g., Tai Chi).</p> <p>AOURP may consider using a saliva test as an alternative option to a blood sample.</p>
<b>Compensation for participation</b>	Electronic Amazon gift card are used by some sites as reimbursement for participants. This is not a helpful way to compensate AANHPIs, especially low SES communities, as most of them are not familiar with Amazon. Also, these communities may not have access to a computer or have knowledge about using the Internet.	AoURP need to create alternative forms of compensation for low SES, immigrant communities, such as cash, cash cards, or Walmart gift cards (physical cards, not electronic) for reimbursement of their community members' time and effort in participating.

**Table 4. Selected metrics of engagement and education of AANHPI populations in AoURP (October 2018-October 2019)**

<b>Metrics</b>	
<b>Number of AoURP promotional events</b>	48
<b>Number of people who attended AoURP promotional event</b>	29,369
<b>Number of AoURP education session</b>	69
<b>Number of people who attended AoURP education session</b>	5643