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Practitioners' Essay

Role of Community Institutional Review Boards in Community Health Center-Engaged Research with Asian Americans, Native Hawaiians, and Other Pacific Islanders

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Abstract

With the growing trend of community-based research, academic-based Institutional Review Boards (IRBs) often lack appropriate community-based ethical considerations in their reviews. Thus, the Association of Asian Pacific Community Health Organizations (AAPCHO) established an in-house community IRB to ensure that AAPCHO or member-initiated research is relevant to its community health centers (CHCs) and their Asian American, Native Hawaiian & Other Pacific Islander (AA&NHOP) patients. Evaluations conducted at the IRB's one-year mark demonstrated members and applicants' satisfaction with the IRB's performance. Evaluation results and best practices show that AAPCHO's IRB promotes community leadership and research capacity and ensures community-applicable research plans.

Background

As more community health centers (CHCs) engage in human subjects research, ethical community-based review of research becomes increasingly pertinent. CHCs play an important role in the US safety net infrastructure by providing care to medically underserved populations, including racial/ethnic minorities and low-income patients. These populations are often underrepresent-

ed in biomedical, health services, or community research. Thus, CHCs are a desirable setting for conducting research with these hard-to-reach populations (Lemon et al., 2006; Riden et al., 2012). Significant CHC involvement in research better ensures that both the research process and results are representative of community interests and needs. Community input in research not only helps address health disparities faced by vulnerable populations but also increases CHCs' capacity to conduct their own research (Oneha, 2012). However, this is achieved through equitable partnership among all research staff, regardless of whether they are academic or community based.

In traditional research, communities are often passive participants, reacting to the needs of researchers. In contrast, community-based participatory research (CBPR) is a model of research in which academic researchers or even researchers from community-based organizations form equitable working partnerships with members to address community-relevant research priorities. In CBPR, communities are not simply sites for recruitment or settings for research. Their strengths and ideas are recognized and used. With significant and meaningful community involvement, community benefits can be realized and both individual and community risks are minimized. In CBPR or other community-engaged research, community members are not merely viewed as research subjects, but they, along with associated community organizations, are equal research partners (Flicker et al., 2007; Horowitz, Robinson, and Seifer, 2009; Hyatt et al., 2009). This shift in the role and contribution of the community raises ethical considerations that may be different from those of traditional research models.

Many community-based organizations often rely on external institutional or academic institutional review boards (IRBs) to review their research. However, these IRBs may lack the community input needed for the review of ethical and quality culturally and linguistically appropriate CBPR or community-engaged research. In 1979, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research published the Belmont Report, which outlines the ethical principles that all researchers should follow when conducting human subjects research. IRBs are tasked to ensure that these principles are upheld in the research projects they review and that individual research subjects are protected. However, IRBs are not required or expected to extend these

principles to the community level (Brown et al., 2010; Ross et al., 2010). Examples of community-specific principles that are not addressed in ethics review include community involvement, partnership building, community empowerment, and mutual capacity building. Traditional ethical reviews mainly function around a biomedical framework in which individual research subjects are the main focus of risk/benefit assessment. Without the appropriate measures and procedures to account for community perspectives, traditional IRBs may overlook risks inflicted on the community due to research (Shore et al., 2011b). Such risks to the community include loss of confidentiality or overgeneralization when research focuses on small populations, stigmatization that may lead to the undermining of social-political authority, and inappropriate dissemination of sensitive data. To address these issues, community organizations have implemented their own ethics review processes and programs, and CHCs have even started to develop and register their own IRBs (CCPH, 2012; Shore et al., 2011a).

One example of a CHC that developed its own IRB is the Waiānae Coast Comprehensive Health Center (WCCHC). Board members of WCCHC, which has long been the target of academic researchers because of its unique patient population and community setting, found that despite the research being conducted in their community, the results from those projects did not translate into any improvement in the health of the community. In addition, the community had no input into the type of research conducted, and often the recruitment and data collection methods were ineffective in gathering the necessary data, or worse, were insensitive to the community. This awareness led a group of community members and CHC staff to develop a set of community research guidelines to guide the types of research that should be conducted in the community, ensure that research methods and tools were culturally sensitive, and require that research provides immediate benefits to the participants and the community. WCCHC established a research committee to use these guidelines to review research requests from external researchers. After a few years of providing this level of community review, WCCHC decided to develop a formal IRB that would incorporate the community protections criteria with standard human subjects protections. This meant that in addition to looking at IRB requirements such as privacy and confidentiality, a comprehensive informed consent process, and

equitable recruitment and incentives, the community IRB required information about community benefits, co-ownership of data, and the process for disseminating research findings to the community and research participants (Oneha, 2012). This community-based research review process has served the WCCHC well; however, it requires a commitment of staffing and other resources that may not be sustainable for smaller CHCs.

Introduction: Development of AAPCHO Community IRB

AAPCHO launched an in-house community IRB to be a resource for all its members and to ensure that AAPCHO- and member-initiated research is scientifically sound, culturally appropriate, and community-relevant. Members have the opportunity to use the AAPCHO Community IRB to substitute or complement external and academic IRBs. AAPCHO is a national network representing thirty-four community health organizations serving predominantly Asian American, Native Hawaiian & Other Pacific Islanders (AA&NHOPIs). The AAPCHO Community IRB not only protects individual rights and welfare but also examines community norms, risks, and benefits. It is also one of the few community IRBs designed in collaboration with CHCs to serve both the CHCs and their AA&NHOPi patient population. AA&NHOPIs are often underrepresented in research, and few studies have specifically addressed health care and outcomes for AA&NHOPIs. Also, research that is conducted on these communities often does not present or collect disaggregated data on AA&NHOPIs, which distorts the actual needs of the many diverse ethnic groups within this population (Ghosh, 2009; Islam et al., 2010). The dearth and misrepresentation of AA&NHOPi data call for strategies to close this research gap, and AAPCHO's IRB is an innovative approach to promote CHC-initiated research in underserved AA&NHOPi communities.

Because CHCs are rooted in the community and their governing boards mostly consist of patients, they are in an ideal position to conduct research to generate new knowledge and identify effective strategies for the unique patient base they serve, including medically underserved AA&NHOPIs (Proser et al., 2007). However, CHCs have to reach out to external IRBs to review their research projects because IRB approval is required for all federally supported research. These IRBs may not recognize the expertise of community leaders – many of whom have research training and experience and

can serve as study principal investigators or coleads. Without an in-house IRB attending to the research involving AA&NHOPIs served by CHCs, community members will continually be regarded as research subjects instead of research partners. One AAPCHO CHC staff member comments on the need for an IRB to ensure equal partnership between CHC and external researchers:

The use of [academic] IRBs, in my opinion, is a short-term solution. I hope we can advance on AAPCHO's plans to develop an IRB that would cover CHCs. Otherwise, I think we will keep having to face this issue...Without such things in place, it does appear like CHCs are viewed [as] more of a recruiting site rather than equal research partners that can house and help analyze research data and subsequently use research findings to articulate our messages.

There is a great disparity in federal funding to support research at CHCs serving AA&NHOPIs (Ghosh, 2003; Trinh-Shevrin et al., 2012). To receive federal research funding, health centers may have to partner with academic institutions, wherein the CHC may lose control and ownership of their research studies and data. Another AAPCHO CHC staff member comments on AAPCHO's IRB potential to enable CHCs to be research leads:

Having an IRB housed at AAPCHO will put our community health centers in the driver's seat so that we can do the work that fits with our mission and values, independent of academic institutions. We can be the applicant organization in charge of our own budget without most of the funding going directly to the academic institutions that usually have unusually high indirect rates.

Limited research funding, the lack of access to other IRBs, and cost limitations due to high university or commercial IRB fees may hinder the research process or prevent these health centers from conducting their own research that aligns with their values and missions. These constraints prompted AAPCHO to develop an in-house IRB, which will empower CHCs to lead their own research projects, increase CHC capacity in human subjects research and partnership building, and engage and educate community partners on the importance and process of an IRB.

The development of the AAPCHO Community IRB started in 2011. Application forms, policies, and procedures were developed

with the help of templates and best practices provided by existing IRBs that serve CHC or special populations. IRB members were recruited from AAPCHO member CHCs and AAPCHO's National Research Advisory Committee, and final members were approved by executive leadership, based on criteria set in the committee's policies and procedures. All contributed to the development of the IRB's purpose, mission, and vision and provided input on all IRB materials, including the policies and procedures manual that was subsequently approved by the AAPCHO Board. AAPCHO ensured that the members were a multidisciplinary team, representing different perspectives of the AA&NHOPi community, but were all still experienced in community-based research. The IRB membership consists of experienced academic and community researchers. There are eleven full members and four alternate members. Half of the membership are members from CHCs, including research directors, coordinators, CEOs, and physicians. The other half consist of academic researchers (professors), community member (private consultant in community-based research), and AAPCHO staff. While there are some members who are less experienced in research, they work closely with the community on a regular basis (Likumahuwa et al., 2013). In September and October 2012, all members completed human subjects protection training via the National Institutes of Health's online course "Protecting Human Subject Research Participants," the Collaborative Institutional Training Initiative's courses, and online training provided by universities and Kaiser Permanente. They also received IRB orientations from AAPCHO that covered the IRB review process; federal rules and regulations; human subjects research considerations; roles and responsibility of IRB members and staff; and the purpose of AAPCHO's community IRB. The orientations emphasized the IRB's intent for protecting community concerns and welfare. For example, in contrast to traditional IRBs, AAPCHO's Community IRB provides time for the applicants to speak directly with IRB members about their projects, and the IRB is knowledgeable about communities' linguistic and cultural needs to protect community members from potentially harmful or sensitive questions. As stated in the policies and procedures, one of AAPCHO IRB's missions is to "provide a strong foundation of knowledge to facilitate the conduct of community health services research at AAPCHO and AAPCHO member organizations" (AAPCHO, 2013). IRB staff members have also attended a multiday training for IRB administrators, conducted by

the Public Responsibility in Medicine and Research (PRIM&R). The training covered topics related to how to effectively implement and strengthen a human research protection program. The IRB held its first bimonthly meeting in February 2013 and accepts applications from AAPCHO members, free of charge.

Evaluation Results

At the AAPCHO Community IRB's one-year mark, in January 2014, evaluation questionnaires were administered using the Survey Monkey web survey tool to both IRB members and applicants to assess their experience and satisfaction with the IRB. In year one, the IRB conducted seventeen reviews, which included both full and expedited reviews for resubmissions, proposed modifications, and revisions. The evaluation questionnaires were adapted from the Institutional Review Board Researcher Assessment Tool developed by the Children's Hospital, Boston, MA (Keith-Spiegel and Koocher, 2005). They were sent to all fifteen IRB members and five applicant research teams. A total of eleven IRB members completed the survey, and a total of six applicants replied (two responses were from the same applicant organization). In the evaluations, close-ended questions were divided into four different topics, including committee meetings, committee members, chair and vice-chair, and administrative support. Scores for the evaluations' closed-ended questions ranged from one (poor) to five (excellent). Open-ended questions were about community-based review, differences between AAPCHO and other IRBs, and the sustainability of the IRB. The applicant evaluation had twenty-one closed-ended questions and three open-ended questions, and the member evaluations had thirty-eight close-ended questions and four open-ended questions. Respondents shared successes, limitations, and areas for improvement.

For the member evaluation, the number of responses received for each individual item ranged from four to eleven, as some members skipped some questions that were not applicable. All scores were 4.0 or higher, except for the following four topics: community representation in committee (3.8), amount of orientation provided to members (3.6), amount of training/education provided to members (3.6), and alternate reviewer system (3.5). Mean scores overall ranged between 3.5 and 4.7. Most reviewers were satisfied with the selection and appointment of the committee members (4.5), members' discussion of appropriate ethical issues (4.6), and the

committee's expertise for protocols under review (4.4). They also felt that the facilitation of the meetings allowed for all members and researchers to voice their opinions (4.7) (see Table 1). Recurring themes from the open-ended responses included proper communication and coordination by AAPCHO IRB staff, collaborative learning among members, and appropriate representation of CHC perspectives. For improvement and sustainability of the IRB, members recommended recruitment of more community members, including patients and clinicians; more training and education for IRB members; and increased visibility of the IRB.

For the applicant evaluation, the number of responses received ranged from five to six. All scores were higher than 4.0, except for the topic regarding the IRB webpage (3.6). Mean overall scores ranged between 3.6 and 4.8. Most of the applicants' and IRB members' scores and responses were consistent in terms of the collaborative and supportive nature of the IRB, members' sensitivity to community and AA&NHOPi concerns and interests, and members' awareness of the CHC setting. For example, the applicants were satisfied with the committee's consideration of ethical issues (4.8) and the suggestions and recommendations made by the committee (4.6) (see Table 2). The recurring theme for both members and applicants is that the IRB captures the needs and concerns of the community.

Discussion

One of the key strengths of the community IRB process is the opportunity for the research team to speak with the IRB about their study, including protocols, recruitment, data collection, and data analysis. This face-to-face/telephone dialogue, which occurs after the review of the materials and prior to the voting on the application, allows a chance for all involved to participate. Researchers often feel this is more of a collegial process compared to one in which an authoritative body reviews and approves study materials without a context in which the research will be implemented. IRB members feel that this process helps them to contextualize the research framework and, in some instances, better understand the nuances of the study and communities of interest. This interaction in no way reduces the rigor with which the IRB reviews and approves the application, as applicants are not present during the deliberation and voting sections of the IRB meeting. In most instances, this interaction has enhanced the understanding of the study and application.

Table 1: AAPCHO Community IRB Member Evaluation Questions and Mean Scores

1. Committee Meetings			
	Range	N	Rating
Time to discuss new protocols	4-5	10	4.3
Time to discuss amendments/revisions	4-5	10	4.4
Time to discuss administrative and educational issues	2-5	10	4.1
Length of IRB meetings (two hours)	2-5	10	4.0
Frequency of IRB meetings (bimonthly)	4-5	10	4.4
Opportunity to participate in discussion	3-5	10	4.3
Criteria for evaluating protocols	3-5	10	4.4
Criteria for determination of final action	2-5	10	4.4
The committee's consideration of ethical issues	2-5	10	4.4
The committee's consideration of regulatory issues	2-5	9	4.4
The committee's consistency in its deliberations and decisions	3-5	10	4.4
Primary reviewer system	4-5	10	4.5
Time and support for expedited reviews	3-5	9	4.4
2. Committee Members			
	Range	N	Rating
Selection and appointment of committee members	4-5	11	4.5
Members' basic understanding of regulations	3-5	10	4.4
Members' discussion of appropriate ethical issues	3-5	10	4.6
The committee's expertise for protocols under review	3-5	11	4.4
Community representation in the committee	2-5	11	3.8
Amount of orientation provided to members	1-5	10	3.6
Amount of training/education provided to members	1-5	10	3.6
Alternate reviewer system	3-4	4	3.5

3. Chair and Vice Chair			
	Range	N	Rating
The Chair/Vice Chair's time allocation for discussion and resolution of issues	4-5	10	4.5
The Chair/Vice Chair's facilitation of the committee meetings	4-5	10	4.7
Encouragement from the Chair/Vice Chair for all members and guests to voice their opinions	4-5	10	4.7
4. Administrative Support			
	Range	N	Rating
Time for members to review protocol materials prior to the meeting	3-5	10	4.3
Time for applicants to send in their Intent-to-Submit	3-5	7	4.4
Time for applicants to send in their applications	3-5	8	4.3
Submission limitation process (one expedited and two full submissions per round of review)	3-5	10	4.2
Organization of the protocol materials	3-5	10	4.3
Organization of other meeting materials	3-5	10	4.3
AAPCHO's IRB webpage	2-5	8	4.1
Use of Dropbox to access documents for review and meeting materials	1-5	10	4.1
Development and maintenance of policies and procedures	3-5	10	4.4
Amount of staff support for the committee	3-5	10	4.4
Letters to PI containing actions and discussions of the committee	3-5	10	4.5
The minutes' reflection of meeting proceedings	4-5	10	4.5
Report of expedited/exempt reviews	2-5	9	4.3
Communication of regulatory and policy issues	4-5	10	4.4

Table 2: AAPCHO Community IRB Applicant Evaluation Questions and Mean Scores

1. Committee Meetings			
	Range	N	Rating
Amount of time for discussion with the committee during the meeting	4–5	5	4.6
The committee’s consideration of ethical issues	4–5	5	4.8
The committee’s consideration of regulatory issues	4–5	5	4.6
Consistency of the committee’s deliberations and decisions	3–5	5	4.2
Suggestions and recommendations made by the committee	4–5	5	4.6
2. Committee Members			
	Range	N	Rating
Selection and appointment of committee members	4–5	5	4.8
Members’ basic understanding of regulations	3–5	6	4.2
Members’ discussion of appropriate ethical issues	4–5	6	4.7
The committee’s expertise for protocols under review	3–5	6	4.0
Community representation in the committee	4–5	6	4.7
3. Chair and Vice Chair			
	Range	N	Rating
The Chair/Vice Chair’s time allocation for discussion and resolution of issues	4–5	6	4.7
The Chair/Vice Chair’s facilitation of the committee meetings	4–5	5	4.8
Encouragement from the Chair/Vice Chairs for all members and guests to voice their opinions	4–5	5	4.6

4. Administrative Support			
	Range	N	Rating
Amount of time given to respond to the initial review	4–5	6	4.7
The Intent-to-Submit process	4–5	5	4.4
The application process	4–5	6	4.5
AAPCHO's IRB webpage	3–5	5	3.6
Clarity and comprehensiveness of policies and procedures	3–5	6	4.0
Letters to PI containing actions and discussions of the committee	4–5	6	4.5
Clarity and promptness of correspondence	4–5	6	4.5
Communication of regulatory and policy issues	3–5	6	4.2

Community IRBs also bring a strong community research lens to the review process. The IRB members' community research knowledge and experiences highlight processes for recruitment and engaged participation, for example, in regards to understanding the importance and values of culturally and linguistically appropriate materials. Often, IRBs ask for translations of materials; however, they do not always recognize the nuances that are involved in the translation process and overlook the details that must be taken into consideration to ensure quality translations within an appropriate context. Translation services are fairly popular, but quality services in which materials are not just literally translated, but also translated around sensitive community and health issues, are not as common. IRB members take to heart the importance of material readability not only in English but also in diverse languages and cultures in which literacy is limited. These types of diverse experiences enrich the accessibility of participant engagement in research studies of underserved communities. IRB members also have experiences working with smaller diverse communities and subgroups, and recognize the burdens of research on these communities. Their inquiries into human subjects protections are extensive. For example, they want assurances of available mental health support services in cases where issues brought

up during research may evoke previous traumatic experiences for participants. This is no different from most IRBs, but community IRBs tend to take it a step further to ensure that culturally and linguistically available support services are made accessible to research participants, especially around sensitive topics such as HIV/AIDS research. IRB members are adamant about ensuring access to appropriate services for study participants to minimize community or societal risks and to ensure community protections.

Community IRBs also hold researchers and research studies accountable to the communities that they have researched. While peer-reviewed publications and conference presentations are important in advancing knowledge, community IRB reviewers often ask researchers for dissemination plans that include strategies to communicate findings to communities. This ensures the communities studied get back the data that was culled from them, ensuring that they, too, advance their knowledge about the issues impacting them.

Lastly, community IRBs empower community researchers and community research staff. Often, when community members partner with academic institutions, only academic faculty or academic researchers can lead the IRB application, and the work that community partners put into the study may not be recognized. Community IRBs promote community–research leads and community–researcher partnered applications, which helps to empower the community partners of research studies. Research staff also has the opportunity to dialogue with the IRB members, allowing them to engage in and better understand the IRB review process, aside from completing the IRB application. These are a few examples of the richness of community IRBs' expertise and how it strengthens research ethics.

Best Practices of the AAPCHO Community IRB

IRB Application Forms

AAPCHO's IRB is specifically designed to allow for community-based reviews. Studies have found that university-based IRB review forms and guidelines lack community considerations. In a review of thirty application forms from different academic institutions, Flicker's team found that although all forms asked for a scientific rationale of the research, only four forms asked about

community or societal risks and benefits. Only five forms alluded to concerns with dissemination of results, and only six addressed culturally sensitive approaches to participation (2007). Also, in an analysis of various ethic committees' feedback for a community-based HIV prevention research study, only seventeen percent of the ethical concerns addressed community protections (Deeds et al., 2008). In contrast to other IRB forms, AAPCHO forms explicitly ask questions pertaining to the effect of research on the community, widening the scope of ethical review to the community level. For example, the forms inquire about both individual participant and community benefits from research, community involvement in planning and implementation of the project, and plans for dissemination of findings to the community. The applicants are also asked to provide an explanation for why a study may exclude women or racial, ethnic, and/or cultural minorities. The research team also has to show that it has received support from the chief executive officer of the CHC in which they are conducting research. All applications received by the AAPCHO Community IRB are based in CHCs in which the principal or co-investigators are CHC staff.

Dialogue and Communication Between IRB and Researchers

The IRB's operational and review process is also tailored to accommodate concerns that arise from community-engaged research. Open dialogue between the community researchers and the IRB committee is often cited as a factor in alleviating the tensions between CBPR researchers and IRBs. Otherwise, community research partners do not receive enough guidance on implementation of research tools in the field. For example, research protocols may specify the language that is used in informed consent forms, but neglect to include the process in which informed consent is obtained. IRB committees are recommended to work with CHC staff to ensure informed consent is culturally and linguistically appropriate (Anderson et al., 2012; Riden et al., 2012). In the AAPCHO Community IRB, researchers are closely involved in the review process and are invited to the meetings. So far, all applicants who have been invited to the meetings have attended to answer reviewers' questions and provide clarifications. There is open dialogue between applicants and reviewers to assuage any disconnect between IRB requirements and CBPR processes and needs. From the evaluations, both members and applicants feel that the IRB is more

collaborative compared to other IRBs that they have worked with; the IRB members want to see CHC projects succeed. Strengthening communication leads to a deeper understanding of both parties' roles, responsibilities, and contexts.

Community-Based Research Expertise and Experience

Because IRB members are CHC staff, they have expertise in many of the research topics being reviewed. The reviewers have an understanding of the processes that community organizations and members undergo for research. The IRB members' knowledge and appreciation of the CHC settings establishes mutual trust between reviewers and applicants. They practice the principles of CBPR and research ethics by engaging and involving the communities to be served, as opposed to simply approving research on CHCs and their communities. The committee understands that certain research projects require different levels of approval, such as on the community or CHC level. For example, investigators assured the IRB that they received approval from their community advisory groups in their CHCs and are engaged with them throughout the research project. In addition to review, the IRB also provided feedback and consultation to investigators regarding cultural and linguistic competency, relevance, and sensitivity; recruitment strategies; translation of findings into practices; and data analysis and reporting. For many research projects, the committee ensures that the investigators have safeguards in place to minimize individual and community risks that might result from the presentation of results and dissemination of data. For example, the IRB recommends that investigators have a qualitative data analysis plan or appropriate sample size to ensure that data collected and results generated will be representative of the patient population they are working with.

IRB Membership

Another element of the AAPCHO Community IRB that encourages CHC-initiated research and capacity building is its membership. The literature reveals that many IRBs do not have the adequate number of community members, nonscientists, or unaffiliated members. Or, when there is a requisite membership in traditional IRBs, community members do not feel they received the proper training for IRB review, as compared to their academic counterparts, even though they are tasked with the same role in reviewing appli-

cations. Although community members' knowledge should be valued equally, compared to that of academic members, some were not comfortable expressing their opinions (Grignon, Wong, and Seifer, 2008; Klitzman, 2012). In contrast, during AAPCHO Community IRB meetings and discussions, equal weight is given to all members, with many opportunities for community members to serve as primary reviewers. By being a member of the AAPCHO Community IRB, CHC staff has the opportunity to engage in the IRB process and bring back to their health centers knowledge they have gained in terms of how CHC research projects should be submitted to the IRB. IRB training has been cited as a strategy to remove barriers faced in CBPR and CHC research. Providing IRB training opportunities to community members fosters long-term community capability and deepens the understanding of the entire research process, from conception to IRB approval. Also, participating in IRB activities may enhance the validity of community partners' grant applications. (Hyatt et al., 2009; Riden et al., 2012). Some CHC staff members first learn about the IRB process when they submit their applications, which is challenging if they have never conducted research before or have never independently applied to an IRB. As AAPCHO Community IRB members, they obtain first-hand experience with the IRB process and would already know IRB expectations if they were to submit an application, decreasing possible delays or complications in the review process. Academic members, CHC members, or nonscientific community members are asked for their opinions and are invited to complete reviewer checklists prior to the meeting. Input is gathered from everyone, and all members are able to learn from each other. There is a reciprocal exchange of knowledge, guidance, resources, and best practices between members new to the IRB and those who are currently or have previously been on academic or community IRBs. Capacity is built through dialogue and discussion among IRB members.

Challenges

One of the challenges the AAPCHO Community IRB has encountered is conflict among members' schedules. Because all members are volunteers and participate in the IRB in addition to their regular jobs, some are unable to attend the meetings due to time constraints. For example, some clinicians cannot participate because of their inflexible clinic hours. Additionally, because the locations of the IRB members span nationally and members are

located in different time zones, there is a limited time frame when meetings can be held via teleconference. This also becomes a problem when trying to use the alternate reviewer system to substitute for full members who are absent. Although a few members felt that additional expertise is needed for review and suggested adding more community members to the committee and increasing the use of alternate members, resolving scheduling conflicts has been a barrier to increasing membership.

Another challenge the IRB has faced is the lack of ongoing training, although a number of members came in with extensive prior training, such as previous experience chairing an IRB. IRB members have expressed interest in receiving continued training on IRB and ethical issues, but lack in funding, resources, and staff precludes any formalized IRB trainings or opportunities to attend conferences for members. The lack of resources and funding also limits the number of applications that can be accepted and the number of meetings that can be held. A submission limitation process had to be implemented so that the IRB did not receive too many applications in one review period and applicants did not spend time preparing all required materials and application forms only to have their applications be denied review or put on queue for future meetings. Occasionally, there are too many submissions for one review period, and conversely, no applications are received for other periods. Monthly reminders are sent to the AAPCHO network to submit applications to the IRB, and the IRB is receiving more applications as it progresses, but other methods of informing CHCs of the IRB's existence and usefulness are needed. Also, some CHCs may still be new to research and are unaware of the process for IRB approval or for obtaining a Federalwide Assurance to conduct human subjects research.

The first year of the IRB also posed difficulties in its ability to streamline the application process. Applicants have noted that there are an abundance of forms and that they need to submit a new application for every phase of a CBPR project. They have also suggested incorporating examples of community involvement in the application forms so they have a better understanding of exactly what the IRB is requesting. Applicants also mentioned that some reviewer comments were more programmatic than research related and that there needs to be consistency in all of the IRB deliberations and actions. The IRB has taken into consideration all of

these important suggestions and concerns and is constantly modifying operational procedures, application and reviewer forms, and the IRB webpage containing submission requirements for a more efficient submission and review process.

Potential Solutions and Future Plans

Different strategies were identified and are being discussed among IRB members and staff to address challenges and limitations. First, one of the most mentioned methods is to develop a budget and multipronged approach to fundraising to secure funding for the IRB. This prompted conversations in regards to opening up the IRB to non-AAPCHO members, who would be charged a fee. This can possibly lead to a higher frequency of application submissions and meetings. Others have also proposed dedicating a small number of full-time equivalent (FTE) employees for IRB staff in AAPCHO research grants. Another suggestion was to add IRB-related costs in federally negotiated indirect rates. Second, the AAPCHO IRB can consider partnering with central IRBs and other existing efforts in CBPR, such as the Community-Campus Partnerships for Health, to leverage resources and knowledge. The IRB can merge with other AAPCHO-member, institutional, or community-based IRBs but still maintain its members who have expertise in CBPR, CHCs, and AA&NHOPi-related issues. Another plan that the IRB is currently focusing on is the recruitment of more community members, including patients, health center board members, and physicians. Although all members have community-based research experience, having more members who work directly with patients or the community will increase community awareness in the review process. Also, possible fees that may be charged for non-AAPCHO member organizations can be used to compensate for a community member's or patient's time and effort in the IRB. Lastly, AAPCHO's vision for the future of its IRB is to establish a network of experienced CHCs and partners to train other CHCs about research and IRBs. CHC staff can sit in on meetings and observe the IRB process. This not only fosters capacity among CHCs members but it also helps publicize the IRB because more information about the IRB is being circulated among the network. Efforts to increase capacity for other members are in AAPCHO's strategic plan, and AAPCHO has a Board Research Advisory Committee consisting of CHC staff and community members that will assist

with the continuing development of AAPCHO's IRB and member CHC research capacity.

Conclusion

Despite the difficulties encountered by the AAPCHO Community IRB, overall, both IRB members and applicants considered the community IRB to be a valuable resource. Members have intimate knowledge of the AA&NHOPi community and CHCs, and are collaborative and responsive in their reviews. The community IRB ultimately increases CHCs' capacity to conduct research independent of academic institutions, producing knowledge that will specifically benefit their communities.

Acknowledgements

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MORGAN YE, research assistant at AAPCHO, provides research and administrative support for the research team, including the Partnership in AA&NHOPi Comparative Effectiveness Community Health Applied Research Network (PACE CHARN) project, in which she collaborates closely with community and academic partners to increase CHCs' research capacity. She is also the IRB coordinator for AAPCHO's Community IRB, where she works with the committee to ensure ethical review of community-based research. Ms. Ye received her Bachelor of Arts in Public Health and Bachelor of Science in Nutritional Science from the University of California Berkeley.

JACQUELINE TRAN is currently an independent consultant doing work in the field of public health with nonprofit organizations. Her interests have focused on access to care, health disparities, cancer health disparities, and working with diverse communities in a culturally and linguistically appropriate manner. In particular, her research has focused on community-based and community-engaged research and its role in capacity building and sustainability for community-based organizations. Dr. Tran received her bachelor's degree in biology and Asian American studies, Masters in Public Health, and Doctorate in Public Health in Health Policy and Management at the University of California Los Angeles.

RACHELLE ENOS has been with the WCCHC for twenty-five years; she currently chairs the WCCHC Research Committee and IRB and facilitates the Research Community Advisory Group (CAG). Ms. Enos assists both internal and external researchers in navigating through the WCCHC research submission process so that proposals are consistent with WCCHC research policies and procedures, and facilitates researcher engagement with the CAG. She also serves as an IRB member for Papa Ola Lokahi (research conducted through the Native Hawaiian Health Systems). Ms. Enos received her Masters in Public Health from the University of Hawaii at Manoa.

ROSY CHANG WEIR, PhD. As director of research at AAPCHO, Dr. Weir oversees the research department including the Community IRB and Data Warehouse. She leads and collaborates on national projects including the Community Health Applied Research Network, Hepatitis B technology intervention, standardized social determinants of health risk assessment protocol, the impact of enabling services, and PCORI research training. She has also served as an expert advisor on HRSA and PCORI initiatives. An immigrant from Laos, Dr. Weir received her Bachelor of Arts and PhD in Psychology at the University of California, San Diego and Santa Cruz, respectively.



Cover Photo Story

Health Care is a Right, Not a Privilege

“Health Care is a Right, Not a Privilege” was the motto for the first Health Fairs offering free services to the Japanese American community in Los Angeles. They were organized by the L.A. Little Tokyo Pioneer Project Medical Committee. In the words of Suzanne [Totsubo] Toji: “We used this picture in the early 70s for the Health Fairs with Dr. H. Ishida and Dr. Warren Nagata giving flu shots and simple exams, Drs. K. Sonoda and Dr. Bob Nishikawa giving dental exams. We’re talking probably 1971-73 when the original Pioneer Project

with Mo (Nishida), John and Tomi Ohta, Ken and Louise Izumi, June and Harold Wong, Kiyoshi and Mitsu Sonoda, Bob Nishikawa, Lily Yasuhara, Doris Kusumoto, and myself, Suzanne Totsubo, were doing Health Fairs for Isseis (first generation from Japan) in the Little Tokyo and Seinan areas. . . I would guess John Ohta might have taken that pic at the Weller Street Health Fair and blew it up.”

In the picture, Nick Nagatani, Vietnam veteran and member of Yellow Brotherhood, carries Nishioka-san, an Issei, down the stairs after he received his free chest x-ray. This became an iconic poster of the Los Angeles Asian American Movement for “serving the people.”

In Nick Nagatani’s own words: “Nishioka-San was in his late youth when he immigrated to Amerika. He worked as a houseboy and studied English. When he became proficient in English, he enrolled in high school where he did well enough to gain admission at UC Berkeley. At Berkeley, he worked and studied and earned a degree in Biology. Upon returning to Los Angeles the war broke out and he remembered incidents such as neighborhood kids throwing rocks at him and calling him a ‘Jap.’ After the war, despite his educational background and college diploma, he could only find manual labor because no one wanted to hire Japanese. He never married because the immigration laws were restrictive in allowing Japanese women’s immigration to America, plus it was unheard of during his time for an Issei to have a relationship with a white woman.”

“When I met him, he was in his physically declining years. Mentally he was sharp as a tack, but a degenerate arthritic condition impaired his mobility to such an extent that when walking, his gait was limited to approximately 6 inches. In all my encounters with him, he was ALWAYS positive, appreciative and even when he shared his personal history which included incidents of systemic and personal racist attacks, he never displayed or harbored any bitterness. Anyway, he was my inspiration.”

—Mary Uyematsu Kao

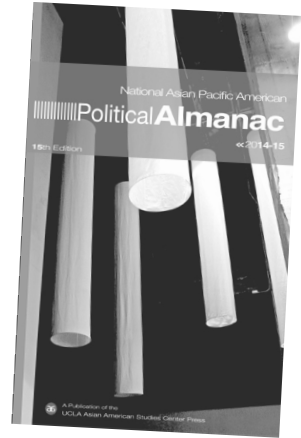
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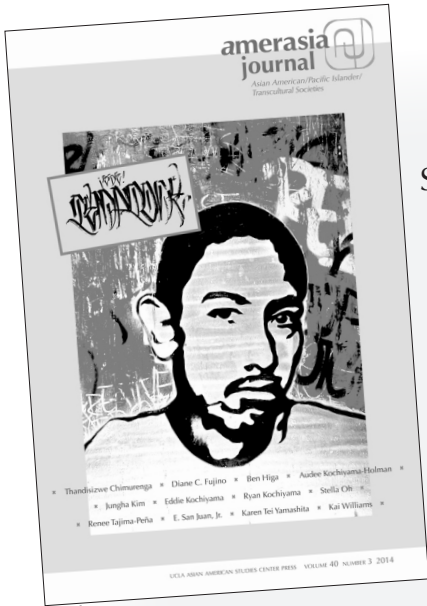
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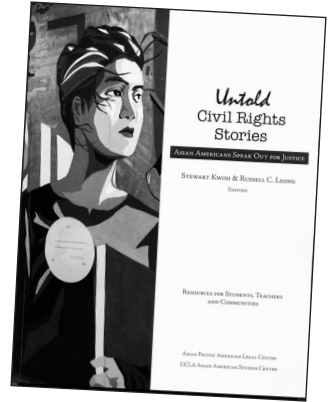
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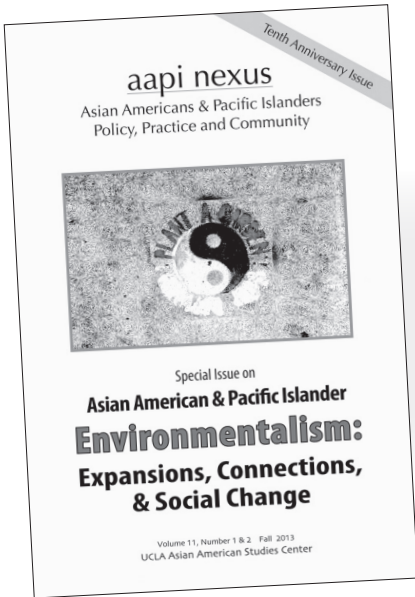
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