

Developing an AAPCHO Institutional Review Board (IRB)

The Association of Asian Pacific Community Health Organizations (AAPCHO) represents 29 community health organizations across the United States serving over 400,000 patients annually. Our health centers are at the forefront in providing community responsive, financially affordable, culturally proficient, and linguistically appropriate primary health care services that improve the health status and access for medically underserved AA&NHOPi populations. With the growing research that our member organizations conduct, an Institutional Review Board housed at AAPCHO would be beneficial to increase capacity for ethical and quality culturally and linguistically appropriate research.

This fact sheet outlines the benefits for developing an Institutional Review Board (IRB) that is specific to ensuring that AAPCHO or member-initiated research is relevant to our members and their communities, has scientific merit, and conforms to high standards of research integrity.

WHAT IS THE PURPOSE OF AN AAPCHO IRB AND HOW DOES IT FUNCTION?

AAPCHO would like to establish an IRB to conduct the following:

- Build research infrastructure and capacity among members
- Empower community programs and partners in the IRB process and to be equal research partners
- Engage and educate community programs and partners on importance of IRB
- Ensure research is culturally and linguistically appropriate.
- Give a voice to under-represented communities in research, especially involving human subjects
- Provide guidance for human subjects protection

A coordinator would communicate with and run activities for the IRB. The IRB would accept applications on a bimonthly or as needed basis for review, and application forms would be available on AAPCHO's website for download. IRB members would review all new funding applications and renewal requests from mem-

ber organizations that do not have their own IRB.

HOW WILL THE IRB BE MAINTAINED?

The coordinator in charge of IRB activities would maintain and record all applications, document all processes, coordinate application review requests, communicate with applicants any necessary steps to take, and provide workshops and TA on research design, methodology, and human subjects protection.

Recruitment of IRB reviewers will come from AAPCHO's National Research Advisory Committee (NRAC), staff or affiliates of AAPCHO's member organizations, and relevant AAPCHO staff and Board of Directors. Support for the IRB will come from financial grants, minimal application fees, member dues, volunteer participation by IRB members, and in-kind support of efforts and meeting costs.

Due to competing priorities, AAPCHO would accept an average of 5 - 10 applications per year (not including renewals).



"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 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".
~ AAPCHO CHC staff

"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 who usually have unusually high indirect rates."
~ AAPCHO CHC staff

USEFUL RESOURCES

Here are a few resources that you can look up for further information about Institutional Review Boards.

Selected articles on community IRBs and building community research capacity:

- Navajo nation IRB: a unique human research review board has three primary concerns: protecting its community, its people, and its heritage. *Prot Hum Subj.* 2003 Spring;(8):1-2. <http://www.science.doe.gov/ober/humsubj/spring03.pdf>
- Braun KL, Tsark JU, Santos L, Aitaoto N, Chong C. Building Native Hawaiian capacity in cancer research and programming. A legacy of 'Imi Hale. *Cancer.* 2006 Oct 15;107(8 Suppl):2082-90.
- Brugge D, Missaghian M. Protecting the Navajo People through tribal regulation of research. *Sci Eng Ethics.* 2006 Jul;12(3):491-507.
- Colwell-Chanthaphonh C. Self-governance, self-representation, self-determination and the questions of research ethics--commentary on "Protecting the Navajo People through tribal regulation of research". *Sci Eng Ethics.* 2006 Jul;12(3):508-10.
- Hernandez JAA. Blood, lies, and Indian rights: tribal colleges and universities (TCUs) be coming gatekeepers for research. 2004; 16(2). <http://tribalcollegejournal.org/themag/backissues/winter2004/winter2004hernandez.html>
- Kagawa-Singer M, Park Tanjasiri S, Lee SW, Foo MA, Ngoc Nguyen TU, Tran JH, Valdez A. Breast and cervical cancer control among Pacific Islander and Southeast Asian Women: participatory action research strategies for baseline data collection in California. *J Cancer Educ.* 2006 Spring;21(1 Suppl):S53-60. http://www.leaonline.com/doi/pdf/10.1207/s15430154jce2101s_11
- Oneha MF; Beckham S. Re-examining community based research protocols. *Pacific Public Health* 2.11:1;2004.
- Schrag B. Research with groups: group rights, group consent, and collaborative research commentary on "Protecting the Navajo People through tribal regulation of research". *Sci Eng Ethics.* 2006 Jul;12(3):511-21.

Selected examples of independent community IRBs:

- Special Service for Groups (<http://www.ssgmain.org/>) and the Orange County Asian Pacific Islander Community Alliance (<http://www.ocapica.org>) co-founded and developed a community-based Institutional Review Board (IRB) in Los Angeles, California. A broad group of community-based organizations and community leaders support the IRB and serve in several capacities, such as IRB members. About the IRB: http://www.cbcrp.org/publications/newsletters/2006/page_17.php
- Waianae Coast Comprehensive Health Center research and IRB policies/procedures: www.wcchc.com.
- American Public Health Association conference audio-recorded presentation: A community perspective of CBPR methods: The Promoting Access to Health for Pacific Islander and Southeast Asian women program: http://apha.confex.com/apha/134am/techprogram/paper_131797.htm
- Papa Ola Lokahi: <http://www.papaolalokahi.org>: Native Hawaiian Health Care System (NHHCS) – Institutional Review Board (IRB): http://www.papaolalokahi.org/hoec2/index.cfm?wwa_ID=93B99296-EF41-4D27-9ECEB62C082DD382&sub=yes
- Navajo Nation Human Research Review Board: <http://www.nnhrb.navajo.org/>

National resource:

- Office for Human Research Protection [OHRP] is a major resource of the federal government: <http://www.hhs.gov/ohrp/>

TERMINOLOGY

INSTITUTIONAL REVIEW BOARD (IRB): A committee designated to approve, monitor, and review research involving human subjects. IRB approval is required before undertaking research mandated by the federal government.

BENEFITS

- Increased capacity by AAPCHO and member CHCs to conduct research
- AAPCHO's member communities would hold ownership of the data
- AAPCHO would serve as conduit to provide oversight on human protections
- Member organizations become more aware of IRB process
- Empowerment of communities' role in IRB process

MORE INFORMATION

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