The National Collaborative Study of Community-Based Processes for Research Ethics Review: A Cross-Case Analysis

Redefining Research Ethics Review: Case Studies of Five Community-Led Models
I imagined…the outline of a fish. You have that main bone going all the way from the tail all to the head. And connecting to all these outlying bones…there are similarities, which was the main bone of the fish, leading from the beginning, the tail to the head…it signals everyone is on a developmental line, ending with what we consider self-determination. And what are those main things that we’re all trying to do here? It has to do with research, need, protection, authority, advocacy, and making it all work. Because the whole fish is really ‘research’ and how we can make life better for all of us. The whole fish really is bringing together our communities with science and scientists.

In thinking about the shared guiding core values of the “fish”, team members spoke about the importance of communication, advocacy, community-centeredness, protection, cultural appropriateness, self-determination, and transparency. The fish metaphor further touched upon the importance of a healthy environment, or as one study member shared, “we had to be careful what you put in the water so that it promotes growth and healthfulness and thriving and try to eliminate the toxicity.”

Continuing with the fish metaphor, the study team displayed an interactive poster at Community-Campus Partnerships for Health’s 13th International Conference, April 30-May 3, 2014 in Chicago, IL. We asked conference attendees that walked by to write on a colored construction paper fish what matters to them in ensuring that community-engaged research is done right. The photo on the cover of this report shows the result. The core values and practices that resonated with the study team were echoed and expanded upon by the more than forty people who participated. Their responses included:

- Nothing about us without us!
- We don’t work for free.
- All the community-based participatory research work must lead to change…policy, systems, institutional or social change.
- Listen to the community. Respect the people. Show up. Follow through.

A copy of the poster along with a complete list of participants’ responses can be found at: https://ccph.memberclicks.net/conference-presentations.
About the Co-Sponsoring Organizations

Community-Campus Partnerships for Health (CCPH) is a national non-profit membership organization that promotes health equity and social justice through partnerships between communities and academic institutions, including those that involve research. CCPH's strategic goals are to leverage the knowledge, wisdom and experience in communities and in academic institutions to solve pressing health, social, environmental and economic challenges; ensure that community-driven social change is central to the work of community-academic partnerships; and build the capacity of communities and academic institutions to engage each other in partnerships that balance power, share resources, and work towards systems change. http://ccph.info

The University of New England School of Social Work embraces a comprehensive definition of health as a state of complete physical, emotional, social, and spiritual well-being and not merely the absence of disease or infirmity. We believe that health, defined in this way, is a universal right. The majority of human suffering is embedded in inequity in the distribution of resources, with vulnerable populations at greatest risk. Thus, our focus is on changing those structures and relationships that foster the inequities that undermine the promotion of health. The School realizes this goal by teaching empowering theories for practice and developing collaborative relationships based on mutuality and respect, at all levels, from direct practice to societal movements. http://www.une.edu/wchp/socialwork

The Center for Community Health Education Research and Service, Inc. (CCHERS) is a community-based organization that is a communityacademic partnership established in 1991 with a $6 million grant from the W.K. Kellogg Foundation’s Community Partnerships in Health Professions Education initiative. The partnership is comprised of Boston Medical Center, the Boston Public Health Commission, Boston University School of Medicine, Northeastern University Bouvé College of Health Sciences and an established network of fifteen community health centers serving the racially and ethnically diverse populations of the City. Northeastern University serves as its host institution and sustaining partner. http://cchers.org

The Galveston Island Community Research Advisory Committee (GICRAC) is the brainchild of a devoted community researcher and concerned community members in Galveston, TX. Serving as gatekeepers for the health and well being of the African American community in the Galveston County area, GICRAC strives to bridge the gap between community and research through bidirectional education and meaningful and relative engagement in community-based participatory research activities.

Guam Communications Network (GCN) facilitates increased public awareness of the issues concerning the Chamorro people and culture through education, coalition building and advocacy. While we focus our efforts on the Chamorro community, we collaborate with other community-based service organizations in order to foster solidarity in our diverse communities and work together toward common goals. http://www.guamcomnet.org/

Papa Ola Lokahi’s (POL) mission is to improve the health status and wellbeing of Native Hawaiians and others by advocating for, initiating and maintaining culturally appropriate strategic actions aimed at improving the physical, mental and spiritual health of Native Hawaiians and their ‘ohana (families) and empowering them to determine their own destinies. One of its programs, POL Institutional Review Board (IRB), seeks to offer community and cultural perspectives that are lacking in other IRBs, an objective that is critical in light of the distrust by Native Hawaiians of researchers and the research process. The POL-IRB recognizes that, despite past wrongs, research focused on improving health programs is valuable for Native Hawaiian communities. http://www.papaolalokahi.org/

Special Service for Groups (SSG) is a nonprofit multi-service agency incorporated in 1952 that serves some of the hardest-to-reach populations across Los Angeles County. Since 2003, our Research and Evaluation Unit works with other nonprofit organizations and community members to collect and analyze information they need for planning and action. We believe that information is power, and we invest in developing these research skills within our communities. To this end, SSG established an Institutional Review Board in 2004 to ensure ethical research practices and equity between academic researchers and community members. http://www.ssgmain.org/
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The Collaborative Institutional Training Initiative (CITI): The CITI Program at the University of Miami is a leading provider of research ethics education content in the United States. Its mission is to promote the public's trust in the research enterprise by providing high quality, peer reviewed, web based, research education materials to enhance the integrity and professionalism of investigators and staff conducting research. https://www.citiprogram.org/

Community-Based Participatory Research (CBPR): CBPR is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change. (W.K. Kellogg Foundation, 2001). http://cbprcurriculum.info

Community-Engaged Research (CEnR): In research, community engagement is a process of inclusive participation that supports mutual respect of values, strategies and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest or similar situations to address issues affecting the well-being of the community of focus. Community engagement is a core element of any research effort involving communities. It requires academic members to become part of the community and community members to become part of the research team, thereby creating a unique working and learning environment before, during and after the research (NIH Council of Public Representatives, 2008). http://www.nih.gov/about/copr/reports/index.htm

Community Review Process (CRP): An abbreviation used throughout this report referring to a community-based process for research ethics review, including federally recognized community-based institutional review boards as well as community-based research review boards and committees.

Federalwide Assurance of Compliance (FWA): The FWA is a contract that an organization signs with the federal government allowing research involving human subjects to take place. It is the only type of assurance of compliance accepted and approved by the U.S. Office of Human Research Protections for institutions engaged in non-exempt human subjects research conducted or supported by the U.S. Department of Health and Human Services. Under an FWA, an institution commits to HHS that it will comply with the requirements set forth in 45 CFR part 46, as well as the Terms of Assurance (HHS, 2011). http://answers.hhs.gov/ohrp/questions/7142

Institutional review board (IRB): An IRB is a committee established to review and approve research involving human participants. The purpose of the IRB is to ensure that all research involving human participants be conducted in accordance with all federal, institutional, and ethical guidelines. In the United States, IRBs are regulated by the U.S. Department of Health and Human Services. http://hhs.gov/ohrp

Public Responsibility in Medicine & Research (PRIM&R): PRIM&R is a non-profit organization with a global membership comprised of those working with research ethics, human research participant protections, animal care and use, and biosafety that advances the highest ethical standards in the conduct of biomedical, behavioral, and social science research through education, membership services, professional certification, public policy initiatives, and community building. http://primr.org
The bulk of the research is from the majority of the population. … Why is it that for the groups that we represent, whether it be native groups or an ethnic group… there seems to be just that inherent thought that anything goes. So… individually we push, but I think even more so…this is a chance for us to come together and… make a group statement… to combine all of these fronts and say … business as usual is just not going to happen. …Because for so long…we’re seeing all the same kinds of things…but how do we get past that? … How do we get beyond Tuskegee?

-Co-Investigator John M. Cooks, Galveston Island Community Research Advisory Committee

In order to more fully understand the operations and impact of community-based processes for research review, Community-Campus Partnerships for Health (CCPH) and University of New England (UNE) partnered with five community-based organizations (CBOs) to conduct in-depth case studies of their community-based review processes (CRPs) and analyze the cases for cross-cutting themes and recommendations. See table 1 for the name and location of each CBO and type of CRP it operates.

Table 1. Community-Based Study Partners

<table>
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<tr>
<th>Name of Organization</th>
<th>Location</th>
<th>Type of CRP</th>
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<td>Center for Community Health Education Research and Service, Inc. (CCHERS)</td>
<td>Boston, MA</td>
<td>Emerging review committee</td>
</tr>
<tr>
<td>Galveston Island Community Research Advisory Committee (GICRAC)</td>
<td>Galveston Island, TX</td>
<td>Research review committee</td>
</tr>
<tr>
<td>Guam Communications Network (GCN)</td>
<td>Long Beach, CA</td>
<td>Research review committee</td>
</tr>
<tr>
<td>Papa Ola Lokahi (POL)</td>
<td>Honolulu, HI</td>
<td>Community IRB</td>
</tr>
<tr>
<td>Special Service for Groups (SSG)</td>
<td>Los Angeles, CA</td>
<td>Community IRB</td>
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Data collection in year one of the study included the following for each of the five case studies: 1) structured interviews with review administrators and chairs 2) a focus group with reviewers and 3) review of key documents guiding the review process. In addition, structured interviews were conducted with researchers for the four sites with an operating community review process and an observation of a review meeting was completed for two sites. In year two, the study team gathered in-person to engage in a focus group discussion with the goal of further identifying CRP promising practices and making
recommendations. The discussion was informed by the study team’s experiences with assessing community-engaged research and their critical review of the individual case studies. The study aims and methods are further described in the first chapter of this report.¹

This cross-case study report discusses the similarities as well as the differences between the five CRPs; makes recommendations for key stakeholder groups, including community groups interested in developing or strengthening a review process, institution-based Institutional Review Boards (IRBs), funders and policy makers; and articulates important next steps. These recommendations and next steps aim to support emerging as well as existing CRPs and contribute to a more nurturing research environment for communities.

### Similarities Across CRPs

**Mission, history and commitment to capacity building**

The passion in which the reviewers from across the different sites come to the table was very inspiring. There was such a clear idea of why people were at the table. Everyone could strongly point to “it’s about the community, it’s about doing the right thing, it’s about respect, it’s about justice.”

- Study Principal Investigator Nancy Shore, UNE and CCPh

All five CRPs developed to ensure community voice in defining research, ensure ethical research, protect the community in their interactions with researchers and build community capacity. They shared an underlying commitment to the communities they serve and a similar history in their origins. While each CRP serves a distinct geographic or racial/ethnic community, all focus on underserved populations. Each CRP began out of concerns around how research was conducted in their communities, with POL-IRB and GCN responding to previous research abuses. Co-investigator Lola Sablan-Santos from GCN spoke to the challenges the Chamorro community had experienced with research, drawing a connection to the history of POL-IRB.

We were all concerned with the way academic researchers were doing research on our communities… the [Native Hawaiian] women [in the POL case study] who said that researchers had come to her family and did all this research because of a genetic situation, and they weren’t given any information and told anything about it. And then again, two years later they still hadn’t received any information. Same like GCN, with the Chamorros… about the helicopter research. They come in… take the information and never come back… So all of us were focused on how are we going to ensure that research done on our communities is ethical, but we as a community will be able to say yay or nay we want to participate in it… We’re all focused on making sure the communities are protected and that we want more community involvement.

The CRPs in our study also share a commitment to community capacity building. As co-investigator Eric Wat of SSG IRB shared,

One commonality is really capacity building on a couple of levels. One is capacity building for the organization in terms of having infrastructure to do the research. But I also see capacity building in individual community members… for those who served in the review process especially to become better researchers. But… really looking at community members, not only as research subjects, but potentially as researchers themselves, right? So their function is not just to do outreach for the academic researchers, but
Similarly, the CRPs also share a commitment to building the capacity of academic researchers to enhance their abilities to effectively engage with communities. While all the review processes work with the researchers who are submitting proposals for review, POL-IRB also provides training free of charge to medical students at one of their local universities.

Community and cultural considerations
Community and cultural considerations are considered by CRPs in research reviews, and may be embedded in the application questions or through the process, such as in the reviewers’ checklist (SSG, GICRAC, POL-IRB) and in the requirement that the academic and community partners attend the review meeting together (SSG). The value of requiring community and academic partners to attend together, as shared by co-investigator Eric Wat, SSG IRB, is for the review committee to really “see what the dynamics are… are they on the same page about what needs to happen? Do they talk to each other? Do they seem like they have a good relationship?” In thinking about similarities across the sites, Study Coordinator Alice Park, CCPH spoke to how each of the CRPs are committed to “leave a genuine benefit to the community” noting that this is particularly important given the “history of previous research causing harm.”
Table 2 illustrates the types of questions that the CRPs in the study are asking of the research proposals they review, organized by theme (pulled from CRP application forms and reviewer checklists). Many of these questions go beyond those required by the federal regulations to assess community and cultural considerations.

### Table 2. Questions that CRPs Ask of the Research Proposals they Review

<table>
<thead>
<tr>
<th>Theme</th>
<th>Questions</th>
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| Justification for research   | - What is the community/communities of interest for the proposed research?  
- How have you solicited community input to determine research project goals, research questions and potential benefits to the community?  
- Does it fit the mission of the health centers? Does it fit the mission of the community? Does it fit the mission of your organization?  
- What was the motivation for the research and was it community-driven?  
- Is the proposed research focused on a significant or pressing concern to the community? |
| Partnership and equity       | - Will the community be given any kind of recognition for their input and participation in the project?  
- Is the organization partnering with other community-based organizations for this research project? If so, what would be the role and responsibilities of each partnering organization?  
- Are partnership terms equitable/satisfactory to the community?  
- What type(s) of technical assistance, if any, would the organization anticipate needing throughout the course of this research project? |
| Conflict resolution          | - If conflict arises within the community during the research project, how will it be addressed?  
- Are there resources available for the participants if any harm is caused?  
- How is the participant/community informed if there is an adverse event? |
| Data ownership/agreements    | - Who owns the data?  
- How is permission from the community group demonstrated, e.g., is there a memorandum of agreement? |
| Budget                       | - Is there sufficient funding/budget to complete the research?  
- Does the study budget include fair compensation for community partners (including but not limited to the actual study participants) and distribution of resources among partners?  
- Does the community have the capacity to successfully implement the project?  
- How are communities being compensated for their knowledge and time? |
| Community involvement        | - Who are the community facilitators or gatekeepers?  
- How is the community kept informed as the research advances?  
- What happens after the study is over? Will the collaborative be disbanded? Will there be an intervention?  
- Is there a community advisory board?  
- How are community members involved and prepared to actively engage throughout the research process?  
- What is the depth of involvement of all the partners?  
- Is there time for us to become involved, on the study collaborative or on the planning of the study? |
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<thead>
<tr>
<th>Theme</th>
<th>Questions</th>
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<tbody>
<tr>
<td>Community benefit</td>
<td>• How does the process and anticipated outcomes of the research project benefit the community and its various stakeholders? • Does the proposed research bring direct benefits to the community in terms of jobs, capacity, etc.? • What new information will be generated, and how will it be used? • Does the research project/grant proposal have the potential to advance the health in the community of focus?</td>
</tr>
<tr>
<td>Research team composition/</td>
<td>• What is the composition of the research team and is there community representation? • What experiences does the organization have in engaging community and its various stakeholders? • What efforts have you made to ensure that the research team has the sensitivity to understand the social, cultural, and environmental context of the community of focus? • What is the researcher’s experience working in the community? With what communities? Do they have a history with this community?</td>
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<tr>
<td>experience</td>
<td></td>
</tr>
<tr>
<td>Cultural considerations</td>
<td>• Are there cultural harms in this research? If so, how are these being addressed and minimized? • Are efforts to ensure sensitivity to understand the social, cultural, and environmental context of the community of focus convincing?</td>
</tr>
<tr>
<td>Dissemination</td>
<td>• Are participants involved in the presentation? Can they have input on where and how study results are made public? • What happens to study results? Will they be published? If so, where? Will there be a press release in the local paper(s)? Are community members involved in the writing of the final report or article? Will results be presented to the community? Where and how?</td>
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**Community Engagement**

All of the CRPs in the study share a commitment to privileging the community voice in their review considerations. One means of accomplishing this is by examining whether the community is an equal partner in the research. Protocols are reviewed with an eye towards determining whether the community has been engaged in the development, implementation and dissemination phases of the research. This may require, as co-investigator John Cooks, GICRAC describes, adding “back door CBPR” if a protocol failed to include the community in the planning phase, and offering suggestions for greater community engagement in the research moving forward. CRP reviewers consider no community involvement or lacking involvement in a meaningful way as unethical. This would include protocols written exclusively by an academic researcher with no community involvement, inadequate or non-existing stipends for the community, or lack of a mechanism for reporting study results to the community. As shared by co-investigator Lola Sablan-Santos, GCN,

[GCN] turned down [a research proposal as] it was written by the researcher… everything was written by the researcher. Didn’t have any community involvement whatsoever. There was nothing about even providing community with stipends for their participation or even a report.
back and so our reviewers just said flat no…. if you’re talking about CBPR … to have some researcher come in and say, ‘I’ve got this project, I want you involved in it, here it is!’ That’s not right at all. And I think our communities are now savvy to this whole process.

The reviewers also look to ensure communities are appropriately recognized and compensated for their expertise. GICRAC and POL-IRB request researchers submit their budget to determine if the community is compensated accordingly. As co-investigator John Cooks, GICRAC reflected, “we have to say, ‘is it ethical to expect me to hold these meetings every two weeks and then you not provide me the resources to do it?’ Because out of those meetings is going to be everything that you are going to report back on and get tenure.” Money also equates to power, hence the budget review serves as an analysis of power, an important issue particularly for partnership projects. Another example of the budget review as an ethical issue relates to in-kind, such as whether it is ethical to expect a community organization to donate weekly meeting space for a project. As explained by co-investigator Mei-Ling Isaacs, POL-IRB,

It tells you first of all, whether or not you’ve got the money to do the project because a lot of projects go under because they’re under funded. It tells you who’s getting paid. It tells you how much is allocated in the different areas… And if you are truly a partner with a community group, are they getting a fair shake here? As our review says, if you’re a partner, you get one half. That’s what partnerships are all about. But this is ethical for us, these are ethical questions, and we had projects go back to the drawing board to re-allocate some funds, even if it’s already been set. Some of them don’t come to us until after they get their money. So, they just have to go out and get more money.

In discussing the value of reviewing the budget as part of a research ethics review process, other CRPs in the study spoke to how they may now implement this as part of their review process. As co-investigator Elmer Freeman, CCHERS observed, “if we can’t see the budget, we can’t do a review.” Along with the need to look at the budget, the CRPs in the study pointed out the importance of community groups carefully reviewing any sub-contract issued by the involved academic partner and developing more of a relationship with the partner’s fiscal department. Elmer Freeman reflected upon his experiences working with academic researchers as a means to underscore the importance of understanding the fiscal policies of academic institutions:

I have one person that writes the science and then I got six other people that I deal with to get a subcontract. The researcher doesn’t know anything about indirect rates. They don’t know anything about off-campus indirect rates. They don’t know anything about the research administration side of it. … so I put it into our review process. I think it is an educational process for the researchers to deal with the institution. Not only for the community to understand what’s going on, but for the researcher to actually be able to go back and be your advocate within the institution once they get an understanding of it.

Community Benefit

All of the CRPs in the study assess whether the research will leave a sustainable and tangible community benefit. Their definition of “community benefit” includes decisions and actions that occur while the study is underway (e.g., ensuring that community partners own the data, sharing findings with community members in a timely and appropriate format) as well as longer-term benefits that may not be evident until after the study (e.g., examining whether the proposed research will build
capacity for researchers based in the community, will develop transferable skills among community-based study team members). GCN asks specifically about data ownership and control to ensure this information source remains with the community, and all the review processes stipulate that data is not used beyond the stated purpose. As another means of providing community benefit, GCN and SSG examine not only if there is an adverse event protocol that provides resources to individual participants, but request that a referral list be distributed of organizations that provide accessible, affordable services in the language spoken by participants. Such a resource list allows research to leave a tangible benefit to communities after the study has concluded.

As another means of giving back to the community, the CRPs in the study examine whether protocols exist for including the community in dissemination of study findings. Dissemination should go beyond publication in a peer-reviewed journal, and include sharing and discussion of study results in a format that is accessible to the community, such as through community forums and report-outs at community meetings. POL-IRB’s progress reports ask specifically how results were shared with the community. Only POL-IRB has implemented a publications policy requiring the review of the final report and any publications resulting from a study. This allows the community a means to have a voice in how the study findings are disseminated. As explained by co-investigator Mei-Ling Isaacs, POL-IRB,

All of the CRPs in the study also attempt to raise the community voice in research through community capacity building. Protocols are reviewed to determine if community members play a role beyond outreach or as research participants. This might occur by ensuring appropriate support and resources to have community members assist in designing the study, serve as research staff, or actively participate in the dissemination activities. This allows community members to develop valuable research skills that are also transferable to other fields, resulting in long-term benefits for the community as a result of the research.

One of the reasons we have this little thing in there about reviewing final reports or publications has to do with group power. And even though we try to deal with keeping the integrity in the forefront in any research project, it’s what is published, what is put in the report that is actually the last product that can cause tremendous group harm – if it isn’t structured the way that is balanced or reports what it’s supposed to report. Publication is, for us, very, very important in group harm.

Social Justice Orientation

All of the CRPs in the study view proposed research – and their role in research ethics review – through a social justice lens. Social justice requires CRPs to critically assess such issues as power and equity, as well as carefully examine the social, cultural, and historical context of a given proposed study. The CRPs acknowledge that a social justice orientation deviates from what is outlined in the federal human participant regulations, and goes beyond the Belmont Report’s conceptualization of the principle of Justice. A social justice orientation is aligned with the values and intent of the community review processes, and should not be viewed as problematically biased or less invested in scientific rigor. As shared by study principal investigator Nancy Shore, UNE and CCPH,
really stood out in terms of feedback to what the POL process was about. But you consider cultural considerations, you consider historical pieces, and that's somehow deemed 'political'? … There needs to be something that addresses that narrow conception.

**Differences across CRPs**

The people involved in the [GCN] review process just want it to be a review process. They don’t want to establish an IRB that is Chamorro-specific. They just want to review the projects and give input… they just want to be able to review the proposals that are coming to GCN and to say ‘yes’ this is a health disparity that we want to address. Yes we want to participate in this and they’re giving us the opportunity to learn about our community. And that’s what they want now. Whether or not that’s still the case a year from now… I don’t know. But they have control.

- Co-investigator, Lola Sablan-Santos, Guam Communications Network

Differences among the five CRPs fell into three major areas: 1) communities served, 2) structure and 3) practices or policies. For three of the review processes, the communities served are specific ethnic groups: Pacific Islanders in the case of GCN, African-Americans for GICRAC, and Native Hawaiians in the case of the POL-IRB. For SSG, the communities served include mental health consumers, ex-offenders, and people who are homeless. Ultimately CCHERS will be serving individuals who access community health centers in Boston.

In terms of structure, POL-IRB and SSG are federally recognized IRBs, GCN and GICRAC are community-based review processes, and CCHERS is a developing review process. Several times during the focus group discussion, the study team emphasized how becoming a community-based IRB should not be considered an end goal. As Lola Sablan-Santos explains, GCN reviewers do not currently want to become an IRB. Some of the practice and policy differences emerge due to structural differences as POL-IRB and SSG are required to adhere to the federal human participant regulations.

Other practice and policy differences emerged due to community preferences and experiences. Examples of these include:

**Requirement for researchers to attend the review meeting:** SSG and GICRAC require this, while POL-IRB and GCN do not. POL-IRB initially required the researcher to attend the review meeting, but based upon past experiences found that the review process moves more effectively if the POL-IRB administrator works with the researcher in advance of the meeting to sort through potential questions and concerns.

**Written policies guiding the review process:** SSG, GICRAC, and POL-IRB have written policies, while GCN does not. GCN’s decision to have a primarily discussion-based review process reflects the Chamorro culture’s oral traditions.

**Membership requirements:** POL-IRB and SSG reviewers reflect a combination of academic and community members, while GCN is solely community members. While GICRAC has both academic and community members, only the community members can vote on the protocol under review. CCHERS envisions a combination of community and academic reviewers.

**Engagement in developing the research proposal:** GCN and GICRAC review committees are
actively involved in shaping the design of the research proposal before it is reviewed. This includes ensuring proposals are aligned with a CBPR approach. If a proposal has already been written at the time of submission to GCN and GICRAC, the reviewers will work towards achieving “backdoor CBPR.” CCHERS envisions this approach as well. POL-IRB and SSG influence the research design by critically reviewing proposals during their review process.

These practice and policy differences emerge mainly through experiences and context, and should not be interpreted as one way being better than the other. As discussed during the focus group, established procedures may vary across groups depending on such factors as cultural considerations and type of review model used. As an example, GCN policies and procedures are not written given the community’s oral traditions. Furthermore, co-investigator Lola Sablan-Santos, GCN shared,

I think what’s important too is that the community said... ‘hey, that’s the Western way. That’s not our way.’ And... the people who have been involved in the research that GCN has been involved with, they were very adamant that we do it our way, the Chamorro way. We take our cultural values, our traditions, and that’s how we outreach into the community. So when they’re reviewing proposals, why not? I mean who’s to say, I mean it isn’t the federal government... we can tell the federal government this isn’t going to work for us. They may not fund us, but... this is how we do it. And why? It’s like, how dare you tell me we don’t do it this way!

In other words, becoming an IRB is not necessarily relevant or appropriate for all community groups. This could in part be due to resource issues and desired intent of one’s review process.

Two of the key challenges described by the CRPs in the study pertain to inadequate infrastructure and lack of respect or recognition by some within the academic community.

**Infrastructure challenges**
All the CRPs spoke to the challenges associated with securing and maintaining adequate resources to support their review processes. In some instances this manifested as non-existent or insufficient staffing support dedicated to the review process. Limited support negatively affects the extent in which CRPs can function. For example, co-investigator Eric Wat, SSG discussed how limited resources hamper their ability to implement post-approval site visits or even follow-up beyond the annual review requirements. In other instances insufficient support limits the number of proposals the CRP can assess, or limits the ability to provide regular training opportunities for reviewers. Only POL-IRB and SSG have dedicated funds to partially support the review process (i.e., support for CRP administrator’s time). All of the CRPs, however, rely upon their reviewers to volunteer their time and expertise.

In thinking about how funding challenges differ from institutional IRBs, study partners talked about how institutional IRBs are funded in part through indirect costs. Not all community-based organizations, however, have a federally negotiated indirect rate thus eliminating this potential funding source.

**Legitimacy challenges**
The second key challenge focused upon the struggle to be recognized and/or respected by the academic community as legitimate entities – even for CRPs that are federally recognized IRBs and thus theoretically on par with an institution-based IRB. As shared by co-investigator Mei-Ling Isaacs, POL-IRB,
We’re all reaching out to science and researchers to be partners … We’re recognized because of the community and then we have to look over to the federal structure because it gives us authority. It also gives us an opportunity where universities or [institution-based] institutional review boards take us more seriously… And I think we’re all looking for that respect, that kind of mutual respect within our communities and between ourselves and in [institution based] institutional review boards… and beyond respect, I think is a recognition of being colleagues… we’re just colleagues like everybody else and we’re all moving towards the betterment of our people and…being sure research is doing that as well.

Comparison between CRPs & Institutional IRBs

[Institutional IRBs are concerned with] compliance with the grant, the funders, but the community review boards, in addition to some of those same concerns, might also be concerned about the benefit coming back to community, how dissemination happened, the ownership, respect, capacity building…

-Study consultant Elaine Drew

Similarities exist between the CRPs in the study and institutional IRBs. For example, as federally recognized IRBs, POL-IRB and SSG must adhere to the same federal guidelines as institutional IRBs.

Key differences also exist between CRPs and institutional IRBs. As described within the Challenges section, infrastructure resources represent one of the key differences. Overall institutional IRBs are viewed as having greater resources to support their functioning, including funds for staffing support. A second key difference centered on the underlying commitments or focus of CRPs as compared to institutional IRBs. Table I provides evidence for the differences in types of review considerations accounted for by the CRPs. The intentional focus on community and cultural concerns differs from the types of questions prompted by the federal regulations and Belmont Report. All CRPs in the study highlighted the added rigor of their review processes given their application of both traditional regulatory considerations AND community and cultural considerations.

The CRPs in the study also diverged from institutional IRBs in many of their practices and policies. Key differences include the roles they play in research beyond conducting reviews, their membership and voting policies and their practices regarding exempting protocols. Beyond reviewing protocols, GCN and GICRAC are directly involved in conducting research either in partnership with an academic researcher or on their own. GICRAC hosted Listening Tours to hear directly from the community what research should focus on. This helped to ensure community engagement through research that is relevant and useful. Understanding community priorities can then help shape the kind of research to be conducted. As co-investigator John Cooks, GICRAC shared, “I’m striving to get [GICRAC] to the point that we go knock on the [university’s] door and say this is what we’re concerned about, who do you have in here that can help us?” CCHERS plans to serve as a space for academic and community researchers to come together to collaboratively identify research questions. Co-investigator Elmer Freeman commented that while CCHERS will review research, the primary function of its research committee, comprised of half community members and half academics, is to “generate research and create connections between the people who are on the committee.” As another example of a role beyond reviewing protocols, POL-IRB administrator teaches at the medical school to train new students on how to engage ethically with Native Hawaiians in CBPR.
Membership and voting policies differ. All the study partners require that the membership of their review committee is comprised of a majority, if not entirely (GCN), community members. POL-IRB, for example, stipulates a minimum of 50% of the membership be of Native Hawaiian ancestry. These policies contrast sharply with institutional IRBs where there is typically one non-scientific and one unaffiliated member to fill the minimum federal requirement, who may or may not be viewed or view themselves as “community representatives.”

Other practices to ensure community voice in CRP review meetings include SSG’s policy that states each community reviewer should be asked in turn if they have comments. CRP voting practices also reflect a privileging of community perspectives. These include POL-IRB and SSG’s policy that a protocol cannot be approved if a community reviewer disapproves. For GICRAC, community reviewers are joined by research affiliates or individuals affiliated with the local university who participate in the review committee, but do not get an actual vote. With GCN, only community members serve on the committee. All the CRPs in the study also attempt to further strengthen the community voice through training and mentoring community reviewers. Through the experience of serving on a CRP, community members learn about research and ethics review and are ideally better prepared to become researchers as well as serve on other review committees. For example, one of the GICRAC reviewers serves on the local institutional IRB, allowing for increased community representation on it and helping to bridge communication between the institutional IRB and the CRP.

Another difference between the CRPs in the study and institutional IRBs is the frequency of research deemed exempt from human participants ethics regulations. The CRPs in the study reported that they rarely exempted a protocol. Although we did not collect sufficient data to analyze why this is the case, the CRPs felt this is likely due to the community process adding a strong community and cultural lens that identifies concerns possibly not considered by institutional IRBs. As an example, a CRP in the study described how the involved institutional IRB exempted a protocol that they deemed requiring a full review. More specifically POL-IRB required a review as the proposed study involved looking at placenta, which the involved university had deemed medical waste. For Native Hawaiians, however, the placenta holds significant cultural meaning and value, and is anything but “waste.” Table 3 summarizes select practices and policies followed by the CRPs in the study.
### Table 3. CRP Practices and Policies

<table>
<thead>
<tr>
<th>Policy/Practice</th>
<th>CCHERS</th>
<th>GCN</th>
<th>GICRAC</th>
<th>POL-IRB</th>
<th>SSG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focuses on underserved population</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Requires minimum of 50% members from the community</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Allows only community reviewers a vote</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Requires researcher to attend review meeting</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Reviews budget</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Asks how results are shared with the community</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Asks about data ownership</td>
<td>TBD</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Reviews partnership considerations</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Considers community capacity building</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>CRP approval prior to researchers publishing findings</td>
<td>TBD</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Has dedicated paid staff for review process</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Conducts research</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

### Interaction between CRPs & Institutional IRBs

The CRPs in the study shared a number of challenges in their relationship with institutional IRBs, including not having formal agreements in place, inadequate communication, and lack of awareness and respect of the CRP. Since SSG frequently reviews research where there is no involved academic partner, it is understandable they often have no interactions with institutional IRBs. Typically CRPs rely on the researcher to act as a liaison with the involved institutional IRBs. To minimize conflict or other challenges with the involved institutional IRBs, POL-IRB requests the researcher submit the institutional IRB feedback with their application and stipulates the POL-IRB’s decision takes precedence over all other IRBs. Another challenge reported by the CRPs is the lack of awareness among institutional IRBs that they even exist, which may play a role in devaluing their contributions. CRPs express a desire to be recognized as legitimate entities and colleagues by institutional IRBs.

Table 4 summarizes the interaction or relationship between CRPs in the study and institutional IRBs that review the same study protocols.

### Table 4. Interactions between CRPs and Involved Institutional IRBs

<table>
<thead>
<tr>
<th>Interaction with involved institutional IRBs</th>
<th>CCHERS</th>
<th>GCN</th>
<th>GICRAC</th>
<th>POL-IRB</th>
<th>SSG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requires researchers to submit institutional IRB application/materials at time of submission to the CRP</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Requests to see institutional IRB feedback</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Communicates with institutional IRBs</td>
<td>TBD</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Relies on researcher to communicate with institutional IRBs</td>
<td>TBD</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Stipulates that the CRP determination takes precedence over institutional IRBs</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
The CRPs in the study recognize the benefits of strengthening their relationships with institutional IRBs, particularly for community-academic partnership projects that undergo both community- and institution-based reviews. For example, cultivating these relationships might streamline the process for researchers needing to obtain multiple IRB reviews. Better communication and exchanging information might ensure consistency in the materials submitted to both review processes. The POL-IRB administrator shared how they now require researchers to submit all the materials that were submitted to the involved institutional IRB. This practice was prompted by a situation in which a researcher submitted different materials to POL-IRB causing confusion and undermining community trust. Some of the CRPs in the study are working to develop better relationships with institutional IRBs. For example, POL-IRB staff attended a training offered as part of the University of Hawaii IRB’s certification and their participation has helped to build staff-to-staff relationships. 

**CRP Impact**

The impact of each of the CRPs in the study center upon three areas: 1) strengthened research ethics, 2) improved research quality and integrity, and 3) greater community benefit. As described previously, the CRPs provide added rigor by examining research ethics that go beyond federal regulatory requirements. This in turn, as reported by both the CRPs and researchers who had submitted proposals to both a CRP and an institutional IRB, improves the research methodology. As described by co-investigator Eric Wat, SSG IRB, 

> If we involve community members from design to dissemination, your research design will be better. Your methodology will be better…That we all made the improvement in how research is being carried out and that’s because we brought the community voice to the table and by doing that I feel like we are educating, we are improving the way academic partners do things in the community.

Finally, CRPs facilitate greater community benefit. This might be through capacity building activities such as training of community reviewers and academic researchers, or requiring a research protocol to provide adequate resources for community partners. As shared by principal investigator Sarena Seifer, CCPH, “[CRPs] are making a difference in community capacity building and the actual changing of the research and making a difference in people’s lives…co-producing knowledge and mobilizing it.”

**Recommendations**

Recommendations emerged for community groups interested in developing or strengthening a CRP, as well as for institutional IRBs. Other recommendations focused upon policy and funding stream changes.

**Recommendations for community groups**

Recommendations for other community groups focused on four broad categories: Infrastructure, policies/procedures, community focus and mentorship.
Assess infrastructure and identify means to ensure availability of necessary resources. Infrastructure to support a CRP can include dedicated staffing as well as funding to provide training and support to reviewers. Strategies to garner greater support include the possibility of charging a fee for reviews and advocating that the review process is included in the host organization’s budget as its own line item.

Develop policies and procedures that reflect your mission and vision statement, or core principles that guide your work. Some communities may be better served with a community-based review committee rather than a federally recognized IRB depending on cultural and/or community considerations. The list below includes policies and procedures recommended for developing CRPs. Following each category of policies and procedures are examples of the types of questions or issues to be considered. As emphasized numerous times throughout the individual case studies and this cross-case report, community groups should develop a process that best meets their needs and resources while remaining open to change as new needs arise or lessons are learned.

• **Committee membership:** Will your review board include both community and academic partners? What other composition requirements are important given the involved community? How will new members be recruited? Will there be a requirement for a certain percent representation by the community?

• **Committee member training and certification requirements:** How best to ensure reviewers are prepared to assess research proposals? Will training entail completion of an established human participant research certification? Will new reviewers be required to observe review meetings prior to having a vote? What resources exist to assist with training and/or mentorship of new reviewers?

• **Application materials:** To what extent does your application materials reflect your mission/vision statements? In addition to the traditionally required materials (i.e., recruitment materials, consent forms, data gathering instruments), what other materials might help with the review process (i.e., proposed research’s budget)?

• **Review procedures:** What kinds of research will require a full review? Will there be lead reviewers assigned to each protocol? Should the academic researcher and community partner attend the review meeting?

• **Post-approval requirements:** What monitoring mechanisms should be implemented to ensure community and academic partners are adhering to the approved protocol? What publication and dissemination policies should be developed to ensure that 1) the involved community receives the research findings and benefits and 2) potential harm is minimized or eliminated?

• **Research participant bill of rights:** What are the rights and responsibilities of the research participants? What are the responsibilities of the academic and community research partners? How might community considerations be integrated into a participant bill of rights?

Listen to your community and educate researchers to ensure ethical conduct of research. Team members pointed to the Listening Tours that allowed GICRAC to hear directly from the community what research should focus on. Team members also spoke to the tremendous value of educating future as well as current researchers on how to engage ethically with the community.

Develop a system of mentorship and support. The CRPs in the study greatly benefitted from being mentored by other CRPs during their development and pointed out the benefits of CRPs building relationships and consulting with one another to create a learning community. Strengthening of CRPs and enhancing how research occurs may be achieved through mentorship, sharing advice on how to work with institutional IRBs, as well
as exchanging resources (i.e., sample policies and protocols), best practices and lessons learned.

**Recommendations for institutional IRBs**

Membership considerations were the primary recommendation for institutional IRBs. This includes both increasing the number of community members serving on the IRB and ensuring community reviewers are genuinely connected and/or familiar with the different communities involved in the proposed research efforts. Strengthening the community membership on institutional IRBs was felt to be an important strategy for increasing the likelihood that institutional IRBs would take community and cultural considerations into account during their reviews. CRPs are one source of community reviewers for institutional IRBs. A recommendation for both institutional IRBs and CRPs was to increase their coordination and communication. This must be bi-directional. CRPs are encouraged to initiate a relationship with institutional IRBs in their vicinity and any involved in the studies they review. Institutional IRBs are encouraged to investigate whether there are CRPs operating in their midst and reviewing the studies their researchers are involved in, and to initiate communication.

**Recommendations for policy change**

One recommendation for policy change focused on changing how researchers and reviewers gain certification in the ethics of human participants research. More specifically, changes are needed to the usual mechanisms of certification (i.e., CITI) often required of researchers and reviewers. These training mechanisms generally do not include content regarding the ethics of respectfully engaging communities in research. Alternative trainings to CITI that focus on community-engaged research, and including a module on community-engaged research within the CITI training were both recommended. There are some examples of the former but these need to be more widely publicized and utilized.

Policy changes are also needed at the federal level. The Belmont principles and the federal research ethics regulations that derive from them do not adequately cover the scope of ethical issues that arise in community-engaged research. Co-investigator Mei-Ling Isaacs, POL-IRB spoke to the need to establish clearer ethics guidelines that reflect concerns experienced across diverse communities. In essence developing “a certain standard of practice” to be included in human participant research trainings that hold researchers accountable and ensure these practices or rules are “recognized and given the power of law or regulation.”

Having greater community representation on the Secretary’s Advisory Committee on Human Research Protections (SACHRP) was identified as an important step towards greater alignment of federal research ethics regulations and community-engaged research. As stated on the US Department of Health and Human Services’ website:

> **SACHRP shall provide expert advice and recommendations to the Secretary, through the Assistant Secretary for Health (ASH), on issues and topics pertaining to or associated with the protection of human research subjects. The Committee will work to advise the Secretary on how to improve the quality of the system of human research protection programs, including the responsibilities of investigators, institutional review boards (IRBs), administrators, and institutional officials, and the role of the Office for Human Research Protections and other offices within the Department of Health and Human Services.**

Involvement of CRP administrators and chairs as SACHRP members could help to ensure that community-engaged research ethics are considered...
and reflected in regulatory changes. Once these considerations are included in the regulations, the question arose as to whether an institutional IRB would be the appropriate entity to assess whether CEnR is ethical. As study principal investigator Sarena Seifer, CCPH reflected,

If you all of sudden change these rules to include all the community issues we care about… I don’t believe university IRBs are the right place to review that. They’re not constituted that way, they’re already over burdened, over worked, there’s no way they can take on all the community and cultural considerations.

Greater coordination between CRPs and institutional IRBs might be the preferred system for thoroughly reviewing community-engaged research. A final policy level recommendation was to re-think the current IRB structure. As study principal investigator Sarena Seifer questioned, “Why are they even based at institutions? They should have been independent boards to begin with. They should not have been based at a university that does the research, they should’ve been an independent body” with no conflict of interest with the research being reviewed.

Recommendations for funding agencies
The CRPs in our study have experienced variations in funders’ understanding of community-engaged research. The California Breast Cancer Research Program (CBCRP) was identified by the study team as a funder with genuine understanding of the principles of community-engaged research. For example CBCRP has separate budgets for community and academic partners, allowing community partners to be funded directly. In instances where the community partner does not have a calculated indirect rate, CBCRP pays a 25% indirect rate. We recommend that NIH and other funders look at CBCRP guidelines as a model to follow. As co-investigator Lola Sablan-Santos, GCN asked, “why can’t that [CBCRP type policies] then transfer over to NCI, NIH if they’re really promoting CBPR?”

A second recommendation was for funders to invite community-academic research teams to present on their research, including partnership considerations. Similarly, successful community-academic research partnerships should speak to their funders about their experiences as a means to not only raise awareness but to encourage funders to “own” their role in supporting community-engaged research. Ideally this would lead to reinforcing the value funders place on it and ensuring their continued support.

Recommendations for mobilizing knowledge from the study
Based upon a critical review of each case study and the cross-case analysis, the study team identified a number of ways to mobilize the knowledge generated by the study. In particular, we are committed to supporting the growth and development of CRPs to enhance their reach and impact. We will collectively pursue these over the coming months:

- Create guiding documents that help community groups determine what kind of review model best fits their needs and context.
- Develop a research ethics position statement that clearly specifies core community and cultural ethical considerations. Advocate for the adoption of this position statement by national organizations and for its inclusion in federal research ethics regulations.
- Tell our stories of how communities vet research, and encourage other community groups to do the same. Speaking as a group of concerned and knowledgeable community groups will help create change.
- Develop “myth-busters” factsheets that address common misconceptions about CRPs.
- Facilitate opportunities for community groups to mentor and support each other in the development and strengthening of their CRPs.
Study Conclusions & their Implications

When we embarked on the National Collaborative Study, we knew that CRPs existed and we were familiar with a number of them through personal experiences, published papers and presentations at meetings. Little was known, however, about their operations and their impact. By examining 5 diverse CRPs in depth, we have documented the significant difference they are making both in the ethical design, conduct and impact of research as well as in the research literacy, capacity and ownership in communities. We have also documented how they differ from institutional IRBs in both their engagement of researchers in the review process and in the community and cultural lens through which they review proposed research. In the case of the two community IRBs in the study, we found they go beyond the federal research ethics regulations to include significantly more community-based reviewers and to assess community and cultural level ethical issues. Along the way, we also refute a number of misconceptions about CRPs: that they prevent research from moving forward and that they do not provide a rigorous and thorough review. We found that the vast majority of studies reviewed by CRPs are approved. CRPs are deeply invested in research that ethically engages communities and responds to community needs, concerns and assets. They take their charge seriously, including developing policies and procedures, recruiting and preparing reviewers, and investing in ongoing professional development. Their reviews often entail a back-and-forth process between the CRP and the research team to address concerns raised by the CRPs, ultimately resulting in a more ethically sound, feasible and rigorous study design.

Our study findings point to a critically important role for CRPs in research ethics review that is not being fulfilled by institutional IRBs. For CRPs to fully actualize this role, the challenges facing their development and sustainability must be addressed. First and foremost, financial resources are needed to support them. CRPs have been creative in supporting themselves on a shoestring budget. Institutional IRBs are able to support themselves through indirect funds from research grants that CRPs are largely unable to access. We believe the federal government – as the major supporter of health research in this country – must invest in CRPs as a key component of the national research ethics review system. A promising first step would be to provide competitive grants for the start-up of new CRPs and the development/expansion of new CRPs.

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Citation
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