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Community-Based Research Should Be Based in the Community

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In the first issue of *Progress in Community Health Partnership* (PCHP), Editorial Board Chair Claude Earl Fox posed some excellent questions for consideration by academic researchers and community-based programs.¹ His questions concerned the ability of academia to make community-based participatory research (CBPR) a priority, the sharing of power between academia and community in CBPR, and incentives for academics and community to engage with each other. Perhaps his overarching query was this: “What is the most effective way to involve community in research without controlling the process through the intimidation of the degree?” His stated goal for PCHP was to offer a forum to help “expand the inventory of effective models of [university–community] cooperation.”

In our guest editorial for this special issue of *PCHP*, we present an example of an effective model of collaboration. `Imi Hale—Native Hawaiian Cancer Network is a program in Hawai`i that leverages community and university resources to reduce cancer health disparities experienced by Kanaka Maoli (Native Hawaiians), the indigenous people of the Hawaiian archipelago. As you will read in several of the articles in this special issue, Native Hawaiians with cancer are more likely to be diagnosed with late-stage disease and are more likely to die than Caucasian Americans.² The National Cancer Institute (NCI) recognizes the need for targeted cancer programming and research in disparate communities and, through its Center to Reduce Cancer Health Disparities, funds 25 Community Network Programs across the country.³ `Imi Hale (pronounced EE-ME HA-LAY) is one of these programs (U01-CA114630).

The overall goal of `Imi Hale is to reduce cancer incidence and mortality among Native Hawaiians by maintaining and expanding an infrastructure that (1) promotes cancer awareness within Native Hawaiian communities, (2) provides education and training to increase cancer prevention and control research by Native Hawaiians, with the goal of developing more Native Hawaiian researchers, and (3) facilitates the application of evidence-based information to reduce cancer health disparities through the development of policy and the translation of science into cancer prevention and control practice.

`Imi Hale's work is guided by CBPR principles and empowerment theory, both aimed at strengthening the capacity of Native Hawaiian individuals and communities to identify their own problems and advocate for their own solutions.² Since 2000, Native Hawaiian Nā Liko Noelo (Hawaiian for budding researchers) have completed more than 35 research projects, developed more than 20 new educational curricula and products, and published more than 80 manuscripts in peer-reviewed journals. We could identify only three Native Hawaiian researchers in 2000; since then, more than 14 Native Hawaiians have completed or enrolled in doctoral degree programs and are pursuing research, and 30 more have completed or enrolled in medical school or masters degree programs.

`Imi Hale's model of cooperation is quite simple. This program is based in the community, rather than the university. Papa Ola Lōkahi, a community organization dedicated to Native

Hawaiian health and well-being, won the first NCI Cooperative Agreement for `Imi Hale in 2000 and has provided a home ever since.

Three groups guide our work (Figure 1). Our 10-member Community Council (100% of Hawaiian ancestry) advises on the cultural appropriateness of the research, researchers, and program activities. Our 10-member Scientific Council (50% Native Hawaiian) advises on the scientific merit of research projects. Our 11-member Steering Committee (73% Native Hawaiian) establishes policy and approves research pilot projects. Collectively, these groups provide key avenues to increase Native Hawaiian leadership and participation in cancer prevention and control.

Collaboration is critical, and partnerships with more than 60 entities have been formalized through memoranda and contracts. Examples of clinical partners are: the five Native Hawaiian Health Care Systems (NHHCS) providing access and prevention services to Native Hawaiians on the state's 7 inhabited islands; The Queen's Cancer Center, Hawai'i's largest provider of tertiary (and cancer) care; and the Hawai'i Breast and Cervical Cancer Control Program, provider of breast health care, for medically uninsured and underinsured women. Examples of program partners include the American Cancer Society and the Association of Hawaiian Civic Clubs with over 50 clubs nationwide. `Imi Hale is an active member of the state's cancer and tobacco coalitions, and participates in regional (e.g., Hawai'i Comprehensive Cancer Control Program and Micronesians United) and national coalitions (e.g., Asia Pacific Program for Empowerment and Leadership, Intercultural Cancer Council, and the Education Network to Advance Cancer Clinical Trials). Examples of educational and research partners include the University of Hawai'i (UH) and Oregon Health and Sciences University (OHSU). Another key partner is the 19-member (84% Native Hawaiian) NHHCS Institutional Review Board (IRB), administered by Papa Ola Lōkahi, which provides a community-based, community-sensitive review body for our research.

To achieve a robust, community-based research infrastructure, `Imi Hale outlined specific roles for university affiliates. For example:

- `Imi Hale's Principal Investigator is a Native Hawaiian oncologist who also is medical director of a local cancer center and has a UH affiliation.
- `Imi Hale's Research Director is a UH professor of public health who designates 70% time to Papa Ola Lōkahi through a contract to the University. Her work is done in consultation and collaboration with the Program Directors at Papa Ola Lōkahi. They work together with the Principal Investigator to guide all program and research activities.
- `Imi Hale's Scientific Advisory Committee includes researchers from local universities and research institutes. Their role is to advise on research design and feasibility of research projects undertaken by `Imi Hale and its Nā Liko Noelo.
- `Imi Hale provides mentoring, technical assistance, and program assistance to university-based Native Hawaiian researchers who win cancer research awards both through `Imi Hale or independent of `Imi Hale. Pilot project awards through `Imi Hale's cooperative agreement are subsequently subcontracted to the researcher's university for management.
- The NHHCS IRB membership includes researchers from UH and other organizations who assure respect for communities and are sensitive to community concerns, such as data ownership and group harm, as well as protection of individuals participating in `Imi Hale research projects.

- UH, OHSU, and other academic partners provide training and technical assistance in research and writing to Nā Liko Noelo. The central activity of our UH-based Research Director is to provide research training and technical assistance to everyone affiliated with `Imi Hale. She also facilitates access to other UH training resources and supports Nā Liko Noelo who enroll in UH courses and degree-granting programs. OHSU has invited Native Hawaiians to participate in its 3-week Native Researcher Cancer Control Training Program, and more than 25 Nā Liko Noelo have completed it.

Our model of university–community collaboration also was used in preparing this special issue of PCHP. In line with the mission of PCHP and CBPR, we called for manuscripts that reported on community-based research and programs, strongly encouraging manuscripts from Native Hawaiian researchers associated with `Imi Hale. In line with our goal to empower Native Hawaiian and other junior researchers, we offered a series of workshops on how to write manuscripts. Ten hopeful writers attended our workshops, with structured sessions on how to write summary sentences, abstracts, and manuscripts. Over the course of 6 months, these 10 trainees developed 13 manuscripts. Eight of these manuscripts were submitted to PCHP for review, along with seven manuscripts from other writers. All submitting authors received mentoring in revising manuscripts to address reviewers' comments, and authors of rejected manuscripts were assisted in revising their manuscripts and submitting them to other journals. Additionally, three of the workshop attendees generated manuscripts for submission to other journals. We hope you enjoy the articles in this issue, all of which feature indigenous and/or junior researchers as authors and reflect the principles of CBPR.

Keeping the accomplishments of `Imi Hale in mind, let's return to Fox's opening question: "What is the most effective way to involve community in research without controlling the process through the intimidation of the degree?" In our minds, the answer is: "Base community-based research in the community, and employ university expertise as needed."

In this model, the locus of control is in the community, and academic institutions are held accountable through memoranda and contracts. The community benefits by being firmly in control of the resources, which increases the likelihood that research projects meet community priorities. Through their roles as advisors and researchers, community members receive tangible benefits from the partnership, including enhanced knowledge, skills, and capacity. For the university, this arrangement demonstrates community commitment, provides "real" access of academics to the community, attracts more community researchers into academic training programs, and produces research leading to meaningful improvements in community health.

`Imi Hale is happy to add our brand of university–community cooperation to the inventory of effective models sought by PCHP. For more information about `Imi Hale and our methods and accomplishments, please contact us at kbraun@hawaii.edu and jtsark@papaalokahi.org.

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Figure 1.
Infrastructure of 'Imi Hale