

BUILDING A RESEARCH INFRASTRUCTURE AT YOUR HEALTH CENTER

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20 YEAR INVOLVEMENT IN RESEARCH

**“Principles and Guidelines for
Participatory Research”**

**“Procedures for Use of Information
and Data”**

was developed and published in 1992



PRINCIPLES & GUIDELINES FOR PARTICIPATORY RESEARCH

1992 “Principles and Guidelines for Participatory Research”

- The community participates in planning the research
- There are direct and immediate benefits for community residents and participants
- Research participants are active participants rather than passive subjects
- Minority members are represented in research projects targeting minority populations
- Data are owned by both community and research agency
- An increased share of resources flows to the community

DeCambra H, Enos R, Segal Matsunaga D, & Hammond OW. (1992). Community involvement in minority health research: Participatory research in a Native Hawaiian community. Cancer Control Research Reports for Public Health. Pp. 2-9



“PROCEDURES FOR USE OF INFORMATION AND DATA

- **Established guidelines for publications, public presentation, and newspaper articles of research findings**
- **Identified a Publications Committee Review process**
- **Described the use of data for program planning**

**Waianae Coast Comprehensive Health Center, Waianae Cancer Research Project,
“Procedures for use of information and data.”(1992)**



STRATEGIC PLANNING MEETING

2002 – with key Health Center & Community participants

- Establish IRB
- Policies & Procedures
- External Research Partnerships
- Develop organizational structure for research
- Plans for long range sustainability
- Education, training, and research career opportunities for staff
- Develop a business plan to support staff FTE and computer equipment & software.



2009

- **Develop methodologies and indicators that look beyond “classic” indicators .**
- **Conduct a community needs survey/ assessment.**
- **Develop a repository of existing WCCHC program evaluations.**



RESEARCH OPPORTUNITIES

**Cultural practices and the impact of culture on health,
Benefits our community,
Impacts morbidity and mortality of the community**

Affect of sociocultural factors on chronic diseases

Acculturation and the development of disease

Focus on the “family” unit

Quality improvement

Oral care

Access to care

Enabling services

Health outcomes, Etc...



RESEARCH INFRASTRUCTURE

www.wcchc.com

- Request to Conduct Research Form
- Data Request Form
- Policies and Procedures
 - Research Committee
 - IRB

RESEARCH COMMITTEE

- **Purpose:** To ensure cultural responsibility, collaboration and equitable resource allocation, with protection of the WCCHC and community as a primary focus.

- **Membership:** WCCHC Staff

- **“Request to Conduct Research Form”:**
 - Collaborative arrangements
 - Fit with goals of WCCHC
 - Identified benefits to the community
 - Tools appropriate for target community
 - Community involvement
 - Cost to WCCHC/Funding to WCCHC
 - Adequate resources (staff time for recruitment and/or implementation, supplies, equipment, etc.)
 - In-Kind (space, staff time, equipment, etc.)
 - Ethical issues
 - Data ownership
 - Data owned by the community
 - Plans for dissemination
 - Expected that findings will be shared with participants/community
 - Findings shared before publication/ presentation



IRB

- **Purpose:** To review approved and funded proposals, provide final approval to conduct research at WCCHC, provide legal oversight and monitor funded proposals with the primary intent of protecting the research subjects
- **Membership:** WCCHC Staff, community member, CHC, faculty from the University of Hawaii
- Scientific merit
- Population
- Implementation Methods
- Risk to participants
- Benefit to participants
- Safeguards
- Informed consent



HINTS TO PARTNERING WITH WCCHC

- Contact us from the time you have an idea
- Significance in the literature vs. priority in the community
- Costs to community sites of non-funded research
- Dissemination to the community
- Publications/presentations require Research Committee review



EXAMPLES OF RESEARCH STUDIES CONDUCTED

- The Development of Metabolic Syndrome in Filipino, Native Hawaiian and Samoan Adolescents "The Hawaii Youth Metabolic Study"
- Prenatal Post-Traumatic Stress Disorder among Low Income Women Living on the Waianae Coast of Oahu
- A Culturally Relevant Risk Reduction Intervention with Native Hawaiian Mothers
- Intimate Partner Violence (IPV): Community Health Centers Take Action
- Improving Diabetes Outcomes Through Community Health Education
- Hawaii Community Resource Obesity Project
- Exploring Community Influences Affecting the Disparities Found in Breastfeeding Patterns on the Waianae Coast of Oahu



RESEARCH EXAMPLE

A Culturally Relevant Risk Reduction Intervention with Native Hawaiian Mothers

Purpose: To address the components of perinatal risk reduction: health promotion, disease prevention, and building effective social support networks using a culturally relevant intervention model.

- UHSON&DH
- Involvement of perinatal support services case managers
- Received training from the University PI
- Participated in Women's Health Day at the Health Center
- Received funding for staff time, incentives for participants
- Involved "support persons" in the visits & education of participants
- Data to support further grants & inform practice



WHY ENGAGE IN RESEARCH?

- *“The staff and resources are already stretched too thin.”*
- *“Who are you going to get to do this and will they have the time to do it?”*
- *“Will this require an additional layer of administrative and financial management?”*
- *“We worked with researchers from the university in the past and the relationship was not necessarily one we would like to experience again.”*
- *“Some providers and nursing staff will remind us of why they joined our CHC. Research was not among their initial reasons for wanting to work with us...”*



BENEFITS TO ENGAGING IN RESEARCH

- **Advances CHC mission**
- **Builds capacity**
- **Function as a recruitment & retention tool**
- **Recognition as a resource/expert**
- **Strengthens grant applications**
- **Improves data collection and reporting**



RESEARCH INFRASTRUCTURE REQUIREMENTS

- Selecting and establishing partnerships
- Development of policies and procedures
- Financial resources
- Human resources
- Hard infrastructure



ENGAGING IN RESEARCH IS NOT THE END, IT IS JUST THE BEGINNING

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