PARTICIPATORY RESEARCH MANUAL

FOR

COMMUNITY PARTNERS

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DEDICATION

To Tuxedo, the little fellow with great big ideas about forming collaborative partnerships and making them come true.

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FOREWORD

In the twenty-first century, knowledge in healthcare is evolving at a geometric rate. In delivering optimal healthcare choices to our patients, we are guided by "best practices", standardized methods developed by experts based on medical research. And yet a void, a "quality chasm", exists between our knowledge and the health of our people. Significant inequalities in health and the quality of life exist between groups of our people. The multiple causes for these differences are not well understood, and solutions to abolish them are even more elusive. More research is necessary to answer these questions.

Given the inequities noted above, a new approach in research has blossomed in the past decade: community-oriented participatory research. A literature has developed for health research professionals, but the adoption of these techniques has been slow, in part reflecting the inequities in distribution of resources and the historical academic consensus about the role of community in the research process.

This Manual is meant as a guide, a primer, for the community worker whose partnership is integral to the community-based research model. The material is presented in a "user-friendly" format, providing a clear review of today's community research environment.

This book reviews some of the history of recent medical research, including examples of poor studies which resulted in breeches of ethics, patient dignity, confidentiality, and even loss of life. Some of us may have had experiences with or known of similar research projects. The manual provides guidance in avoiding mistakes of the past.

The reader will find a discussion of research and its benefits, techniques to create the best research team and advisors, how to conduct a project, and the importance of appropriate sharing of the results with the participants, the community, and the healthcare field. You will read about the evolution in understanding ethics, human dignity, principles of informed consent, and confidentiality. Data collection and interview techniques are discussed in detail, with clear and helpful examples.

Gone is the time when acceptable research simply involved data collection by an academic from "subjects", analysis of that data, and reporting to the scholarly community. This document reinforces the importance of the community's mana'o [understanding] in the development, implementation, and translation of research so that the primary beneficiaries of research are clearly the participants and their communities.

Recognizing that the results of research can lead to powerful advances in health –advances in which all should benefit equally, let us overthrow the bad name research has in many circles. Let's join together to improve the health and wellness of our kupuna, our 'opio, and our mo'opuna!

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PREFACE

The Participatory Research Manual is about involvement in Participatory Research by community partners. The Manual is written to serve individuals who have a wide variety of backgrounds and interests. Some of our readers may be individuals who have undertaken community-oriented research projects. Others may have never tried to access the ideas and information from communities but believe in the value in doing so. Still others may be beginners who want to learn how to navigate through community-oriented research.

The Participatory Research Manual for Community Partners was developed under the Koko'okolu Fellowship in Community Pediatrics, Partnership in Community Pediatric Research, Teaching and Service Project. This Project was funded in 1992 by the U.S. Department of Defense, Tripler Army Medical Center, Pacific Telehealth and Technology Hui. It was through the foresight of U.S. Senator Daniel Inouye, Dr. Calvin Sia, MD, and the Hawaii Dyson Initiative that the development of this rich community-oriented endeavor occurred and blossomed.

The Koko'okolu Fellowship in Community Pediatrics is supported by many organizations:

Pacific Telehealth and Technology Hui, Tripler Army Medical Center

Department of Pediatrics, John A. Burns School of Medicine, University of Hawai'i at Mānoa

Hawai'i Primary Care Association

Hui Mālama Ola Nā 'Ōiwi, Native Hawaiian Health Care System, Island of Hawai'i

John A. Burns School of Medicine, University of Hawai'i at Mānoa

Ke Ola Mamo, Native Hawaiian Health Care System, Island of O'ahu

The goal of the Koko'okolu Fellowship in Community Pediatrics is three-fold:

- Provide a community-oriented participatory research Fellowship for practicing pediatricians,
- Adapt telehealth technology for management and consultation for pediatric conditions
- Design and implement a community-oriented participatory research project

The "Family Perspective of Asthma Project" (Tse, 2002) is the community-oriented participatory research project which provided the stimulus for the Participatory Research Manual for Community Partners. The Participatory Research Manual is written from our experiences with our community-oriented participatory research partnership. In a way, community-oriented participatory research is like a dance. Dancing comes in many different forms, styles, and with different partners. Dancers must compliment each other's steps. Some individuals are "natural" dancers, and others need to practice. However, there is no absolute "correct way" to dance. The Participatory Research Manual is written to excite members of the community towards doing community-oriented participatory research.

ACKNOWLEDGEMENTS

THE AUTHORS

Alice M. Tse, PhD, RN, APRN is an Associate Professor of Pediatrics and Nursing at the University of Hawai'i at Mānoa. She has more than 15 years of experience working with diverse groups and communities on research and forming community-academic relations. Her research interests include community-based studies of pediatric chronic illness and families. Alice received a W. K. Kellogg Foundation Fellowship in 1996, in which she explored how to bring communities and academia together in partnership. She was the Principal Investigator for the Family Perspectives of Asthma Project, which gave us the idea of developing the Participatory Research Manual.

Donna-Marie Palakiko, RN, MS, is the Programs Administrator at Ke Ola Mamo, Native Hawaiian Healthcare System, on the Island of O'ahu. Donna oversees the development for project protocols and program policies. She has worked with Native Hawaiian Communities for 3 years, developing policies and protocols to improve the provision of healthcare services. Donna is currently the Principal Investigator for the Lei Anuenue Mentoring Project. She was the Co-Investigator for the Family Perspectives of Asthma Project.

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ABOUT THE PARTICIPATORY RESEARCH MANUAL

The **Participatory Research Manual** is a guide for community partners to develop their future plans for participation in community-oriented research projects. The Participatory Research Manual is not designed to be a "do-it-yourself" guide to designing and implementing projects. Instead, it is designed for community partners to review and inventory their knowledge about the information and skills needed to become involved in community-oriented participatory research.

Research efforts occur in partnership with many individuals. The experiences of community members guide the team to identify needs and areas to explore. Upon identification of an idea, there are other team members who can assist to determine what should be in a plan and then locate qualified assistance and resources to finalize the plan. It is through collaborative research participation that we can add to the knowledge and practice, thus caring for the community and the individuals.

The Participatory Research Manual is a resource for individuals interested in community-oriented participatory research. The word "research" means to "re-search," or to take the opportunity to "look-again." Providing responsible care means that we continually look and re-look again at what we do, how we do it, and what the outcomes are. This is community-oriented re-search! We believe that communities can do a lot for local problems and achieve very specific results.

Community-oriented research projects provide opportunities for many individuals. There are opportunities to take on different activities and perhaps, try out new skills. Some people prefer one or two tasks; others like to experience the entire range of the project's activities.

Good sense is needed to design a project that is truly meaningful to the community. Sensitivity is needed to assure the project remains responsive to the intent of the community. The Participatory Research Manual will provide an overview of the main ideas associated with a research project.

WHAT'S IN THE NAME?

Many books exist on "community-oriented participatory research." Some related names are: action research, participatory research, collaborative action research, and others. We chose to use the term community-oriented participatory research in this book. The research is oriented to the community, keeping in mind issues of trust, power, dialogue, community capacity building, and collaborative efforts towards the goal to improve community health and well-being. There are roles for everyone. By working in partnership, our intention is to use our skills and values needed to improve our community's health.

Researchable issues come from a variety of sources. The most meaningful ones are usually those from the community's own experiences.

NAVIGATING THROUGH THE MANUAL

Here's how the Manual is organized: Part I sets the stage for community-oriented participatory research. This section describes what research is and identifies the essential elements needed to do community-based research. Parts II and III describes the community component and ethics. Parts IV through VI address the practices for conducting community-oriented participatory research. Part VII offers suggestions on how to answer questions about community-based research.

We've tried to make this Manual fun to look at and read. The colors and extra white space make the pages more appealing. Throughout the Manual, the purpose of the sidebar is to provide examples and tips that are based on our experiences in doing community-oriented research. We do not want our advice and suggested strategies to be rigid. Use the suggestions as a way to get started. Think about how you can adapt the ideas to fit your own work.

About the Tips and Examples, Scenarios and Practice
The Tips, Examples, Scenarios and Practice identify materials that support the ideas in the text.

TIP	TIP shows something that has worked for us and is a good practice to follow.
EXAMPLE	EXAMPLE further illustrates the idea in the text.
SCENARIO or PRACTICE	SCENARIO or PRACTICE indicates a situation where you will need to apply the ideas that you have read to a situation. These are intended to give opportunities to review the content via an application.

SCENARIO: You and your coworkers are a part of a research team that will be looking at the health practices of native Hawaiian elders who have diabetes. Before starting to collect data, the team must finalize the project protocol. The members of the community have some ideas about which topics need to be explored.

How could the team respond?

Answer: In community-oriented research, the experiences of community members guide the team to identify needs and areas to explore. Upon identification of an idea, then determine what should be in a plan and locate qualified assistance and resources to finalize the plan. Everyone brings a different background and experience. At times the differences in interests may not all fit into a single research project. Rather, create several related or "subprojects" to fit the various interests.

PART I: COMMUNITY-ORIENTED PARTICIPATORY RESEARCH

OVERVIEW

Community-oriented participatory research is fun and exciting. Research is like a dance, in that partners must learn to coordinate their steps and actions into a smooth performance. In this Section, we will explore what is "community-oriented participatory research" and the benefits of working together. The concepts that guide community-oriented activities are described. The issues and challenges of doing a community-oriented research project are discussed.

OBJECTIVES

1. Describe "research" and "community-oriented participatory research".
2. Describe the benefits and outcomes of working together.
3. Identify core concepts for community-oriented activities.
4. Describe issues and challenges of community-oriented research.

WHAT IS RESEARCH?

Research is a special form of a project. A research project requires all members of the team to take a logical sequence of steps to look into an issue. Research will help us be more effective when we are working with the community. Our goal is to improve health conditions and assure the provision of primary health care, health education, health promotion, and disease prevention services. Together, in partnership with other individuals and agencies, we work towards improving availability, accessibility, and acceptability of health information and health care services.

Individuals can take on many roles in a research project. The most common are:

- Identifying areas of concern for the community
- Negotiating with other individuals who can serve as consultants and collaborators
- Collecting data about the health status
- Making plans to use the study's findings to address the issues
- Collaborating with other persons and groups

People are naturally curious. We ask many questions about how things work, why things happen the way they do, and what can we do to make things better. Research is a project that is organized step-by-step. A project that is planned step-by-step process will help us answer our questions in a logical way. Research helps us gain information and it is used all the time (for example, in science, marketing, education, politics, and human relations, etc.). Without following a step-by-step process, we may skip over important steps, possibly allowing our explanations to be biased and not logical.

What Is Community-Oriented Participatory Research?

Community-Oriented Participatory Research (COPR) is a type of research that addresses issues that are important to the community and the individuals who live in the community. The goal of community-oriented participatory research is to improve health conditions and assure the provision of primary health care, health education, health promotion, and disease prevention services. Together, in partnership with other individuals and agencies, we work towards improving availability, accessibility, and acceptability of health information and health care services.

Community-Oriented Participatory Research increases the likelihood of long-term sustainability of health programs, ensures cultural appropriateness, promotes socioeconomic development, and transfers skills and knowledge to the community. Issues that are important to the community and the individuals who live in the community are addressed. In other words, this type of research focuses on community practices and viewpoints to improve the health of the community. The community-oriented participatory research process requires collaboration between the researchers, the individuals who live in the community, and the organizations that serve the community (Holkup et al., 2004; Minkler & Wallerstein, 2003).

Most times, individuals who do research do not work by themselves. More commonly, research projects happen when teams of people work together. Each member of a project team contributes their ideas and makes the project stronger because it is built on so many ideas. It will make a project even stronger when the research includes the ideas of the members of the community. This way, we will be able to make sure the project's recommendations will represent the community's views. This is called a **collaborative research partnership**.

The **collaborative research partnership** is based on the following ideas:

- Partnerships can be cooperative, sensitive, and equal. Academics, researchers, consultants, and community partners work together to accomplish research projects in culturally relevant ways and disseminate findings to multiple venues and audiences.
- Communication is attentive, comprehensible, truthful, and advisory.
- Participation is involved, active, and supportive.
- There are job skills training and further employment opportunities for all participants. There are opportunities for further research training and opportunities for learning to approach communities with sensitivity.
- The study team evolves their individual research climate (team culture) by working together.
- Information that is learned will be shared with the community, thus providing opportunities for community self-development and to improve the health of the community.
- The skills and processes developed and used are generalizable (able to be transferred) to other settings, health conditions, and populations.
- Because there are many different audiences, there will be many different venues (outlets) for presenting the information, such as community meetings, brochures, and journal articles.
- A realistic assessment of needs/issues will be obtained and used to direct subsequent community-oriented programming.

Who Are the Participants?

In a community-oriented participatory project, there are many groups of participants. The participants are those whom the research may impact. The community-oriented participatory research approach provides an opportunity for working with many groups. A group may be any collection of individuals who share a similar context, common interest, possibly linked by cultural, social, political, health and economic issues or a geographic location.

We want to make the best decisions about working with individuals and we also want to work to keep individuals healthy. Community-oriented participatory research is a method to give us the knowledge about what is going on in the community, and information on how practitioners can work with the participants to improve health services. Research that involves the community's member's ideas, opinions, and views will help exchange knowledge and information on what is important and relevant for the participants. The knowledge obtained is used for the benefit of all participants, that is, the researcher and community.

BENEFITS OF WORKING TOGETHER

Why Work Together?

There are many benefits that are possible when we work together to develop plans to gather information about the stories and views of the participants. Working together promotes sharing of ideas. Working together develops a common language, understanding, trust, and actions. Each person brings his or her own ideas. When we come together and share our ideas and strengths, we will be able to build a stronger project.

Negotiation and collaboration are needed to be able to share ideas and work together. Each of us comes from many different experiences and has a variety of experiences, so it may take conscious effort to start to work together. Our goal in collaborative community-oriented participatory research is to promote the health status of groups, such as Native Hawaiians, examine health issues faced by the groups and use our strengths to work for the health of special groups.

In general, the anticipated benefits of working together in a community-oriented research partnership are:

- Representation of Native peoples in the National profile.
  Community-oriented participatory research provides opportunities to present and heighten awareness of issues faced by Native peoples nation wide as well as within the State.
- Empowerment of the community to do one's own research activities.
  More information and a better understanding of how the community views health and treatments that are needed.
- Provision of job skills training, skill building, and professional development.
- Enhancement of linkages between the community, agencies, and academia (schools and universities).
- Development of future services.
- Provision of more programs based on research findings.

EXAMPLE

A community-oriented approach for a project may involve everyone who is related to the issue. For example, if the study is about the health of children with diabetes, the parent/caregiver, siblings, health practitioners, and community members are involved.

Parent/caregiver and Sibling
Health practitioner
Community
child
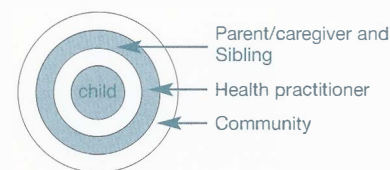
Participatory research considers the many groups that affect the community's health.

SCENARIO: You are working with staff from another agency on a diabetes project. Sometimes it seems it is harder to get things done with all of the individuals on the Project's team.

What are some benefits of working together?

Answer:

1. Everyone brings a different background and experience. We can use these different experiences to draw awareness to the issues faced by Native peoples.
2. We want to improve the health status of Native Hawaiians and one way is through collaborative research projects, where we join forces with the community.
3. Working together gives us opportunities to develop our skills. These may be interpersonal and professional skills, coordination, organization, supportive communication, and problem solving, to name a few.
4. We can develop new ways to link with other agencies, individuals, communities, and academia (schools and university personnel).
5. Working together in community-based research projects will help us improve the health status of our communities.

Results from Community-Oriented Projects

Information is collected primarily for the community to improve the health of the community, children and their families. There are many venues to disseminate and distribute the data from our projects, e.g., at community functions such as health fairs, bulletin boards, posters, parent meetings, brochures, general magazines, and academic publications.

Community Self-Development. The information obtained should ultimately provide information for community self-development. A major aspect of community development is community education. It is through the use of data as the "voice" for individuals, such as children and their families, to tell what works, what doesn't work, and what is preferred that community self-development occurs. One way of "giving back" to the participants who provided the data is to offer access to resources and information or opportunities to tell their family's story.

Communication. There is a need to communicate community perspectives to providers. A community participatory approach aims to facilitate access to care by providing information on what helps and what doesn't help.

Planning Health Programs. Information is crucial for planning health programs in the community. Doing the research is not enough; sharing findings as to what communities find helpful is needed. This will enable realistic planning and development of community-oriented interventions.

RESEARCH AND THE COMMUNITY

Core Concepts for Community-Oriented Activities
There are five key concepts: the role of participation of the community and researcher, the types and use of knowledge produced by the research, the power relationships, the use of the knowledge, and ownership of the data.

Participation. Researchers and community members may have differing needs and agendas. These agendas are sometimes shared and other times conflicting. The main questions are:

- Who represents the community at the community level?
- Who represents the findings past the community level?
- Which realities (findings) are to be revealed (shared) and which are to be kept hidden?

Who represents the community is an important issue. Often agency directors and service providers are asked to serve on community boards, but they may or may not represent their constituents (the individuals they represent). Community members bring richness and reality to the project. Ways of participating for community members include: providing information input, being interviewers and data collectors, participating in the data analysis and interpretation as an advisory group to making recommendations about the project's findings.

Many individuals and groups may represent the findings past the community level. A project advisory may be formed. The advisory should include a representation of the groups that the project may influence. For example, the members of the advisory may be families, parents, older children/teens, community leaders, teachers, coaches, health care practitioners, agency staff, and research team. Members of the advisory team should be selected for their interest and expertise. Expertise may be formal (based on training or knowledge) or informal (based on life experiences).

The contributions of community-oriented academic researchers include knowledge of funding opportunities and expertise about important health issues. Academic researchers may often have to face issues of academic tenure (advancement) and promotion so at times, the need to balance their own job performance demands may make it difficult to maintain a long-term relationship with community partners. Community partners should encourage long-term relationships with academic partners. The ultimate goal is to assure that a legacy will be left over time, thus giving back to the community.

Use of Knowledge. In order to make a change based on the information that is generated from a research project, the research team must demonstrate competence, be connected with the community, and tell the message with confidence. Informal relationships (from our experiences) and formal relationships (what we learn through training) are needed to communicate the knowledge gained.

Power Relationships. There are four types of power relationships: (1) Individuals with situational power make decisions based on knowledge of resources and the existing rules of running a research project; (2) those with hidden power keep some

Laulima or working together with others will result in greater successes.

issues from open discussion; (3) other individuals use power to prevent conflicts from surfacing by favoring certain interests; (4) repressive power is the direct and indirect control over other's opportunities (e.g., education, health, employment, etc). A community-oriented participatory research project will help to work with these relationships.

Use of Knowledge. The relationship between researchers and communities requires trust and mutual commitment over time. There are a variety of venues for sharing the project's findings. The academic researcher may wish to write a professional publication because of the promotion and tenure system requirements at the university.

The community agency may incorporate the findings into an agenda for providing service. Individual community members can exert positive influence on neighborhood boards, school personnel, political leaders, and community leaders, to name a few.

Who "owns" the data? Multiple venues exist for working with the data. Sometimes, the agency or research team may require that authorization is obtained prior to "using" the data. The reason for this requirement is to safeguard the image of the community when the findings are released. There have been instances where researchers have studied community's "problems" but never bothered to report their findings back to the participants. At other times, the research report may seem a bias representation because of the researcher's excitement to illustrate "community problems." Use of the data should be negotiated as the project plans are being developed.

Who decides which realities (findings) are to be revealed (shared) and which are to be kept hidden? An advisory panel could assist the project team to examine the meaning of the results, consider the significance of findings, determine the generalizability of findings, and suggest implications for practice, further study or both. Advisory panel members may bring a new dimension or different perspective and interpretation because they were not present during the project team's discussions.

We encourage all team members to participate in spreading information about the project's findings. When multiple individuals are involved, the individual who takes the lead in a project should have their name listed first, with the key project team's names listed in order of contribution. We also encourage a discussion of how to share the project's findings. All team members can provide insights and ideas. The assistance of other individuals and the project's funding source(s) should also be acknowledged.

Participatory Research and Health Disparities

There are health conditions which affect people of all racial and ethnic groups. However, if we take a closer look at disease rates for racial and ethnic groups, we may find some significant differences. Such differences have been described as health disparities. A National Institutes of Health working group defined health disparities as differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the United States. These population groups may be characterized by gender, age, ethnicity, education, income, social class, disability, geographic location, and sexual orientation.

Many of the differences in disease rates among racial and ethnic groups may be due to factors associated with social class rather than ethnicity. Socioeconomic status (SES) in particular appears to play a major role in the differences in cancer incidence and mortality rates, risk factors, and screening prevalence among racial and ethnic minorities. Moreover, studies have found that SES, more than race, predicts the likelihood of a group's access to education, certain occupations, and health insurance, as well as income level and living conditions, all of which are associated with a persons chance of developing and surviving an illness.

These issues call for creative new approaches that can address such disparities. By its very nature, community-oriented participatory research strategies can address issues of health disparities by relating knowledge to action. Community members are equal partners in dealing with the actions that arise from the project. Community-oriented research focuses on concrete problems and the benefits must relate to the community's needs. In the community-oriented research process, community members apply their insights and experiences to problem solving. The community-oriented research process is a means of involving communities in formulating research questions, collecting and interpreting the data, disseminating and implementing the results (see Figure 1).

An empowering process for all participants

Involves local community capacity building

Community-Oriented Participatory Research

Provides co-learning so that community members and researchers benefit

Balance between doing the research and taking action

Figure 1. Community-oriented participatory research will improve the health and well-being of the community

ISSUES AND CHALLENGES OF COMMUNITY-ORIENTED RESEARCH

There are some unique challenges to community-oriented participatory research. The following guidelines (Harrison, 2001, Holkup et al., 2004) may help outreach workers accomplish their research goal:

- Be flexible but recognize that everyone has limits
- Be willing to collaborate by sharing authority, responsibility, and credit for success
- Give thoughtful attention to the ethical implications of your actions
- Apply the concept of culture in everyday working relationships
- A lot of time commitments are needed
- Change may be threatening
- Project support beyond the funding period is needed

Being flexible and knowing your limits relates to self-awareness. Perseverance and tolerance for discouragement are needed. For example, if the participant does not show up for the scheduled data collection meeting, there is a need for flexibility related to negotiating an alternative data collection session without appearing that the data collector was inconvenienced.

Opportunities may be provided for data collectors to share their experiences at the weekly team meetings. Discussions will help the team and individuals gain self-awareness. In addition, the lead project assistant may attend each weekly team meeting and relay issues and concerns. The issues and concerns will help the team understand ways of working with the community.

Collaborative discussions include all opinions. The opinions from community leaders and participants are actively sought in a community-oriented project. Decision making is accomplished by consensus. The researcher's role is to provide explanations of the usual protocols but suspend judgment. Use a "pilot period" to test the decision that has not been tried before.

Ethical implications involve the issue of confidentiality and sharing the project's results. The research team in a community-oriented project often holds a dual role as the researcher/data collector and community member. As a research team member, individuals are privileged to information they would otherwise not have access.

Some aspects of the project's findings may provide a negative depiction, be damaging to the community or hurt the relationship between the research team and the community. One strategy to obtain feedback prior to dissemination of information is to develop a summary of the dissemination activity to the key members of groups who provided the information for review and consensus.

Enter the community in a culturally appropriate manner. Many times a project's orientation may include a period of orientation "to the community." However, it is not possible to know a culture or community without having lived within the group for a long time. Ideally team members who represent the community will serve as guides for the rest of the team to enter the community in a culturally appropriate manner.

TIP

Keep long-term relationships realistic and easy to maintain.

Determine goals for the relationship and timelines to guide the activities. The relationship should be open to addressing other issues that may develop.

Community-oriented projects require a lot of time commitments. The research team members may develop burnout if the research activity is taken on in addition to the regular workload. We suggest that a contract is written with the community agencies and the agencies are compensated for each individual who participates in the research activity. The goal of the compensation is to allow the agency to hire some staff to fill some of the non-research tasks that were not being accomplished.

Change may be threatening. Taking on a research role can be threatening to the staff and community members. Alternatively, change may be perceived as empowering and an opportunity to try something new. Begin with a small pilot project and communicate frequently and openly about the steps taken and the project's results. When the pilot project is received well by the participants and the data collectors, it will provide a positive foundation for larger efforts.

The project requires supports beyond the research funding period. The goal of having external funding is to get the project "off-the-ground." For a project to become sustainable, the community and agency must desire its continuation. For example, results of project which screened for barriers to pediatric asthma management may be incorporated into the outreach staffs' assessment, or specific programming activities designed to address the identified barriers. The project team may also seek additional funding, building on their past efforts, by writing additional proposals. Lastly, keeping in touch with key community leaders past the duration of the project is needed.

SCENARIO: For your assigned Project, you'll be making home visits at several Native Hawaiian neighborhoods. Your Project team members consist of several individuals who are not Hawaiians and several individuals who are Hawaiians.

Can you suggest a way for all of the team members to get oriented to the communities?

Answers:

1. Don't assume that because of an individual's ethnicity that they have expertise to enter the community in a culturally appropriate manner. Also don't assume that because an individual is not of an ethnic group that they do not have expertise to enter the community either. Consult some elders and leaders of the community. Indicate that you and your team want to learn how to approach the community and be open to suggestions.
2. "Hang out" with the community members, that is, attend community events and really get to know the members. Try to show up at other times, – not only when you are there to collect the data for your project.
3. Credit your success to others in the community who may have paved the way for you and your team.
4. Learn who represents the community and who the spokespersons are. Introduce your team to the spokespersons. Bring someone who has authorized the Project to your meeting.

5. Form a "Project Advisory" group who can advise on issues related to working with community members throughout all phases of your project.
6. Be flexible and know your limits. Community-oriented projects require a lot of time commitments.

SUMMARY

Research is one way to help improve the health of the community. Research activities are not to be undertaken by one individual. Activities are meant to be shared among the team and community partners. Community-oriented participatory research requires collaboration between community members, the researchers, and organizations that serve the community. Working together brings many benefits, including a better understanding of the community's definition of health, skill building, and linkages between agencies and those with research skills. Several core concepts guide community-oriented participatory research activities: participation (who represents the community), relationships (use of relationships to guide the research process), power relationships (how power guides the decision making process), and knowledge (what to do with the findings). Key issues and challenges of community-oriented participatory research include staying flexible and collaborative, maintaining confidentiality, entering the community with respect, the extended time commitments of the project, dealing with change, and supporting the project into the future.

OVERVIEW

In a community-oriented participatory research project, our partners are community members. This type of research does not look at those who are researched as "subjects" or individuals that are to be studied. The opinions and ideas of the members of the community help shape the project and also help us to interpret the findings so the project will make sense within how the community specifically works.

OBJECTIVES

1. Describe ways of explaining research to the public.
2. Differentiate between research and service activities.

EXPLAINING RESEARCH TO THE PUBLIC

When we ask others to help us out, most of the time the first question may be "Why should I help" or "What help do you need?" When we ask others to help us in our research, it is important to tell the participants that we are doing a special project that may benefit the community. Share with the participants what we plan to get from the project and what we plan to do with what we learn.

On a more global level, other participants may want to know that doing research means we will be studying ideas and topics that are important to the community. Information obtained from research is to help communities understand why some things are preferred or helpful to improve the health of the community. It provides us with information about what helps and what doesn't help. The research results can be a useful tool in community self-development and education. The project's results (findings) can also develop community health programming and assist health care providers, organizations, and community leaders in assessing needs.

Don't Underestimate Word-of-Mouth
Word-of-mouth is a powerful tool. Many times, word-of-mouth may be the most effective communication strategy. Word-of-mouth may convey trust in the project, and it may also convey misinformation and mistrust. Because the community-oriented participatory research process requires collaboration between the researchers and individuals who live in the community and organizations, the research team is responsible to take the lead in stimulating community trust in the project.

Respectful Ways of Honoring Participants
In recognition for the participant's time and effort, an "appreciation" (makana) may be offered. The appreciation is not considered an "incentive" for completing the research project; rather, it is a small token of appreciation for the participant's

EXAMPLE

Doing participatory research about what barriers exist for Native Hawaiians who have diabetes will give us ideas on how to develop health programs that fit the community's needs.

assistance. The research team cannot discriminate against those participants who did not complete the project. All participants, even those who do not complete their participation are eligible to receive the token of appreciation.

Acknowledgement of the participants on project reports and presentations is another way of honoring the participants. In addition, providing the results of the project back to the community is a good way to balance the bureaucratic formality of the research project.

Community-Friendly Research Terms

A community-oriented participatory research approach requires community-friendly terms. Use of community-friendly terms promotes trust and collaboration. (See Table 1.)

Table 1. Community-friendly Research Terms

Instead of	Use
Research or Study	Project
Subjects	Participants
Questionnaire	Survey, Forms
Interview	Talk with you (talk story)
Principal Investigator	Director, Supervisor
Staff	Team
Objectives or Aims	"We want to find out about . . . "
Methods or Methodology	"What we will do . . ." or "How we will go about doing it . . . "
Findings	"What we learned . . . "
Implications	"How the information will be used to help us learn about . . . "

SCENARIO: You have been invited to provide an overview of your project to a Kupuna group at the local community church. As you prepare you look over the research protocol...

How will you explain the project?

Answer:

- Instead of research or study use project
- Instead of subjects say participants
- Instead of interviews use talk story
- Instead of objectives or aims say "We want to find out about . . ."
- Instead of findings say "What we hope to learn . . . "

TIP

Provide the synthesized findings back to the group of participants. If the data was collected from an agency or specific group, they may be interested in receiving their raw (unsynthesized) data in order to do further analysis.

Strategies to Communicate Research to the Public

Community-friendly strategies are needed to communicate research. Diversify the project's approach in order to provide the best fit for your project's message.

Try a variety of approaches to promote your project:

- Eye catching fliers (consider readability and avoid jargon)
- Invitation letters ("You are invited to participate . . . ")
- Project website (dedicated website that profiles the project and provides answers to frequently asked questions)
- Word of mouth (promotes trust and clarification)
- Meetings with key individuals and organizations (opportunities at collaboration)
- Publishing the project announcement in agency/school newsletters
- Use a large readable font for printing our publicity materials. (font should be at least 18 points in size.)
- Partner with on-going agency activities (tag along)
- Health fairs (participants are usually interested in improving health)
- Public community events (draws a broad crowd; monitor the newspaper for events)

SCENARIO: You are making a home visit to collect data for a community-oriented participatory research project. Mr. T has agreed to talk with you. Half way through the data collection activities, Mr. T asks you for advice on how to improve his diet because he is concerned that his diabetes will get worse.

What could you do?

Answer:

1. Recognize Mr. T's concern to show you heard him: *"Yes, it sounds like you're thinking about how to make your diet better."*
2. Defer the topic since all research/data collection activities must follow the standardized protocol: *"Why don't we talk about how you can get some information when we're done with these surveys?"*
3. Make a note of Mr. T's concern on a scratch notepad so you don't forget: Jot down: *"better diet"*
4. After the data collection activities, help recall Mr. T's question: *"Mr. T, when we were talking, you wanted to ask me about your diet."*
5. Ask Mr. T if he has talked with his doctor or healthcare practitioner about his question. Provide some general information for referral purposes (the data collector is not the outreach worker, and cannot provide services). The same information must be provided to all research participants if we are talking with individuals in a research context.

We developed a community-friendly image by

- *Using a logo, such as:*

- *Selecting one color of paper for printing all project materials for the public*
- *Using community-friendly research terms*

EXAMPLE

If you are collecting data on O'ahu, bring along the brochure of an agency which can service Native Hawaiians in general. Ke Ola Mamo's (Native Hawaiian Health Care System on O'ahu) brochure is applicable in this case for the participants. The requesting individual should mail the form into the agency office or call the agency themselves because of confidentiality involved.

(NOTE: See the Appendix for an example of a "Services Request Form.")

SUMMARY

We can better engage the community in research if we are open about the project's plans and activities. The purpose of community-oriented research projects is to give us information about what helps and doesn't help. The major way to obtain information is to use "word-of-mouth" to spread the word about the research project and to publicize the project using "community-friendly" research terms. Lastly, research activities are used to identify issues and service activities are used to provide for the needs of the community.

PART III:
RESEARCH AND ETHICS

OVERVIEW

All members of the research team are responsible to maintain research ethics. This section will describe the general principles of ethical conduct, historical events and safeguards, such as research review boards. All members of the research team must be aware of the Privacy Rule for protected health information.

OBJECTIVES

1. Describe the general principles of ethical conduct in research.
2. Delineate the impact of historical events on the establishment of guidelines for researchers.
3. Discuss informed consent, assent and confidentiality.
4. Describe the role and function of research review boards.
5. Describe how the privacy rule protects the way health information is used and disclosed.

ETHICAL CONDUCT IN RESEARCH

Ethical conduct in research means to respect and give consideration to the rights of research participants. Ethical conduct focuses on the:

- Right to anonymity and confidentiality
- Right to freedom from injury
- Right to privacy and dignity

The general principles of ethical conduct are:

- Respect for human dignity (participants are treated with respect)
- Respect for free and informed consent (participants have free choice to participate or not participate and can make individual decisions about participating in the study)
- Respect for vulnerable persons (the research team must account for additional safeguards for certain populations such as children, prisoners, pregnant women (fetus), mentally disabled individuals, or economically or educationally disadvantaged individuals)
- Respect for justice and inclusiveness (participants must be given fair treatment)
- Minimizing harm (participants are protected from unnecessary discomfort or injury as a result of the study)
- Maximizing benefits (benefits of participating in the study must outweigh risks)
- Right to privacy, anonymity and confidentiality (the participant can decide when and how much private information will be shared; the participant's identity will not be revealed and the participant's name is not associated with the data.)

Hilina'i or trust is an important value culturally. Betraying one's trust can result in negative feelings toward research. Ensuring and keeping the confidentiality and safety of each participant's contribution will establish great levels of trust.

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RESEARCH AND HISTORY

History has guided the development of research. It has taken over 70 years to establish guidelines for researchers. At times, researchers actually took advantage of the participants. We have undergone periods in history where poor studies compromised ethical behavior, human dignity, and confidentiality. Loss of life may have occurred in these studies. Some examples of when researchers took advantage of the "subjects" are in the Tuskegee Syphilis Study, the Nazi Experiments during World War II, the Human Radiation Experiments, the Jewish Chronic Disease Hospital Study, and the Willowbrook Study.

Before World War II, few guidelines were available for the protection of human participants in research. Although Germany was the most scientifically and technologically advanced country during World War II, the Nazi party performed unethical experiments. This caused people to lose their trust in the medical community and public health. Because human rights were violated, the Nuremberg Code was developed from 1949-1953 and the Belmont Report was written in 1979. The Belmont Report is known as the defining document which set forth our current code of ethics for researchers.

The following is a timeline of historical research events by year that have shaped the way individuals conduct research:

1930	1940	1950	1960	1970	1980	1990	2000
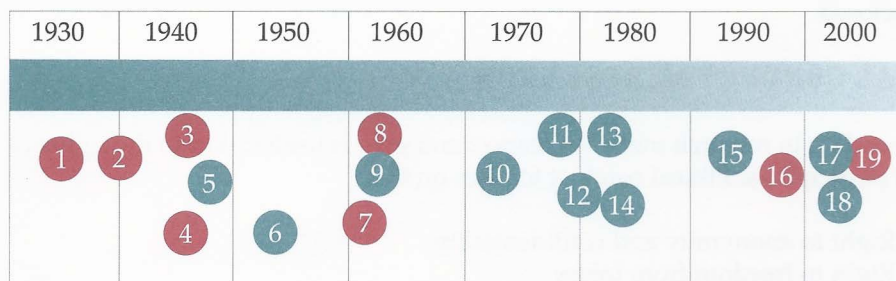
In this diagram, the unethical research studies are labeled with the **red** circles. The efforts to rectify the situation are marked with the **blue** circles. Notice the trend in efforts to protect the rights of participants since the 1960s.

Key to the timeline:

1. Tuskegee Syphilis Study (1932-1972)
Patients with active cases of syphilis were given no treatment even after penicillin was discovered.

2. Nazi Experiments during World War II (1939-1945)
Prisoners' wounds were deliberately infected with bacteria and sulfanilamide was then given to these prisoners to determine the effectiveness of this drug.

3. Human Radiation Experiments (1944)
Photographs and bodily measurements were taken of Jewish prisoners. They were then killed and their bodies defleshed to see if photographs could accurately determine skeletal size.

4 Nazi human experimentation (1942-1945)
During World War II, the Nazi regime in Germany conducted human medical experimentation on large numbers of people held in its concentration camps.

5 Universal Declaration of Human Rights (1948)
Adopted and proclaimed by the General Assembly of the United Nations as a common standard of achievement for all peoples and all nations.

6 Nuremberg Code (1949-1953)
Statement on medical ethics that was issued in 1947 after the trial of 23 medical doctors accused of atrocities committed during the Nazi era in Europe in World War II.

7 Jewish Chronic Disease Hospital Study (1963)
Chronically ill and debilitated non-cancer patients at the Jewish Chronic Disease Hospital in New York were injected with live human cancer cells.

8 Willowbrook Hepatitis Study (1963-1966)
This study involved infecting mentally retarded children with a Hepatitis virus to study the progression of the disease and to test vaccinations that were being developed at the time. Due to overcrowding, children were denied entrance to the Willowbrook State Mental Hospital unless parents enrolled their children into the less-crowded hepatitis ward.

9 Declaration of Helsinki (1964)
Ethical Principles for Medical Research Involving Human Subjects was adopted by the World Medical Association (WMA) in its 18th General assembly in Helsinki, Finland.

10 Federal Legislation for the Protection of Human Participants (1974)
The participation of human beings in research studies is necessary in order to achieve advances in medical and social/behavioral sciences.

11 Belmont Report (1979)
Contains the basic ethical principles that should underlie the conduct of biomedical and behavioral research involving human subjects and guidelines that should be followed to assure that such research is conducted.

12 Regulations for clinical research by Food and Drug Administration (1980)
Development of regulations and laws governing clinical trials and to examine the ethical issues surrounding clinical research.

13 CIOMS Guidelines (1982)
International Ethical Guidelines for Biomedical Research Involving Human Subjects developed by the Council for International Organizations of Medical Sciences

14 1st Policy for the Protection of Human Participation (1983)
It is the responsibility of the institution to insure the protection of the human subjects in such research.

15 Health Insurance Portability & Accountability Act (HIPAA) passes (1996)
National standards for electronic health care transactions and national identifiers for providers, health plans, and employers. It also addresses the security and privacy of health data.

16 Gene Therapy Study at University of Pennsylvania (1999)
A patient died while being a participant in a gene therapy research study. This individual was not fully informed of the risks involved in the research.

<table>
<tr><td>17</td><td>**Office of Human Research Protections established (2000)**
Provides leadership and oversight on all matters related to the protection of human subjects participating in research conducted or supported by the U.S. Department of Health and Human Services (HHS).</td></tr>
<tr><td>18</td><td>**HIPAA Privacy Ruling Effective (2003)**
Includes provisions for the confidentiality and protection of Individually Identifiable Health Information and Protected Health Information.</td></tr>
<tr><td>19</td><td>**Death of a Health Volunteer at Johns Hopkins (2001)**
A 24 year old healthy female employee at Johns Hopkins Asthma and Allergy Center inhaled hexamethonium as a volunteer in a research study. The consent document failed to describe adequately the research procedures to be followed, or failed to identify procedures that were experimental, and failed to adequately describe the reasonably foreseeable risks and discomforts associated with the research.</td></tr>
</table>

The Nuremburg Code

Permissible medical experiments must conform to the ethics of the medical profession generally. Certain basic principles must be observed in order to satisfy moral, ethical and legal concepts:

1. The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; and able to exercise free power of choice, without force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have enough knowledge to make an informed decision.

2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.

3. The experiment should be so designed and based on the results of animal experimentation and knowledge of the natural history of the disease or other problem under study that the anticipated results will justify the performance of the experiment.

4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.

5. No experiment should be conducted where there is an a priori reason to believe that death or disabling injury will occur; except, perhaps, in those experiments where the experimental physicians also serve as subjects.

6. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.

7. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.

8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.

9. During the course of the experiment the human subject should be at liberty to bring the experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.

10. During the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the

exercise of the good faith, superior skill and careful judgment required of him that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

The Belmont Report

Scientific research has produced substantial social benefits. It has also posed some troubling ethical questions. During the Nuremberg War Crime Trials of the Second World War, the Nuremberg Code became the prototype of many later codes intended to assure that research involving human subjects would be carried out in an ethical manner. The Belmont Report contains three principles, or general prescriptive judgments that are relevant to research involving human subjects, and these principles are identified in this statement.

Boundaries between Service and Research. There is a difference between research and providing service (the practice of accepted therapy). The distinction between research and service may be blurred partly because both often occur together (as in research designed to evaluate a therapy). For the most part, the term "service" refers to interventions that are designed solely to enhance the well being of an individual patient or client and that have a reasonable expectation of success.

Service is providing for the needs of the community. We provide service on a daily basis, and by adapting what we do to fit the individual client's needs. The purpose of medical or behavioral practice is to provide diagnosis, preventive treatment or therapy to particular individuals. By contrast, research designates an activity designed to test a hypothesis, permitting conclusions to be drawn. **Research** strives to identify the issues of the community using a logical step-by-step approach. This step-by-step approach is handled the same way for every client, so we can say that approach is "standardized." When an approach is standardized, we can look at the findings for similarities or differences and know what we find is not because of any different approaches.

The following table shows the differences between providing services and doing research. Research and service may be carried on together when research is designed to evaluate the safety and efficacy of a therapy. The general rule is that if there is any element of research in an activity, that activity should undergo review for the protection of human subjects.

Table 2. A Comparison between Providing Service and Doing Research

Service	Research
Providing for the needs of your client or the community	Identify the issues of the community
Individualized approach that fits the client's needs	Step-by-step approach that is standardized
Outreach staff actively intervenes	Outreach staff or data collector collects the individual's story but **does not** intervene
Outreach staff makes referrals for individuals who need assistance	Outreach staff or data collector should drop off referral literature to all participants irregardless of need

RESEARCH gives us new ideas on ways to provide service . . . and SERVICE gives us ideas on what to study further in research.

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Basic Ethical Principles. The expression "basic ethical principles" refers to those general judgments that serve as a basic justification for the many particular ethical prescriptions and evaluations of human actions. Three basic principles, among those generally accepted in our cultural tradition, are particularly relevant to the ethic of research involving human subjects: the principles of respect for persons, beneficence, and justice.

Respect for Persons. Respect for persons incorporates at least two ethical convictions; first, that individuals should have autonomy to make decisions, and second, that persons with diminished autonomy are entitled to protection. An autonomous person is an individual who is capable of making decisions about personal goals. However, not every human being is capable of self-determination. The capacity for self-determination matures during an individual's life, and some individuals lose this capacity because of illness, mental disability, or circumstances that severely restrict liberty. In most cases of research involving human subjects, respect for persons demands that participants enter into the research voluntarily and with adequate information.

Beneficence. Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well being. Two general rules compliment beneficent actions in this sense: (1) do no harm and (2) maximize possible benefits and minimize possible harms.

Justice. The selection of research participants needs to be scrutinized in order to determine whether some classes (e.g., welfare patients, particular racial and ethnic minorities, or persons confined to institutions) are being systematically selected simply because of their easy availability, their compromised position, or their manipulability, rather than for reasons directly related to the problem being studied. Finally, whenever research supported by public funds leads to the development of therapeutic devices and procedures, justice demands both that these not provide advantages only to those who can afford them and that such research should not unduly involve persons from groups unlikely to be among the beneficiaries of subsequent applications of the research.

Applications. Applications of the general principles to the conduct of research leads to consideration of the following requirements: informed consent, risk/benefit assessment, and the selection of participants of research.

Informed Consent. Respect for persons requires that participants, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them. **Information** – consists of the research procedure, their purposes, risks and anticipated benefits, alternative procedures (where therapy is involved), and a statement offering the participants the opportunity to ask questions and to withdraw at any time from the research. Additional items have been proposed, including how participants are selected, the person responsible for the research, etc. **Comprehension** – because the participant's ability to understand is a function of intelligence, rationality, maturity and language, the manner and context in which information is conveyed is as important as the information itself. **Voluntariness** – An agreement to participate in research constitutes a valid consent only if voluntarily given. This element of informed consent requires conditions free of coercion and undue influence.

Assessment of Risks and Benefits. The term "risk" refers to a possibility that harm may occur. The term "benefit" is used in the research context to refer to something of positive value related to health or welfare. Many kinds of possible harms and benefits need to be taken into account. There are, for example, risks of psychological harm, physical harm, legal harm, social harm and economic harm and the corresponding benefits. While the most likely types of harms to research participants are those of psychological or physical pain or injury, other possible kinds should not be overlooked.

Selection of Participants. The principle of justice gives rise to moral requirements that there be fair procedures and outcomes in the selection of research participants. **Individual justice** in the selection of participants would require that researchers exhibit fairness: thus, they should not offer potentially beneficial research only to some patients who are in their favor or select only "undesirable" persons for risky research. **Social justice** requires that distinction be drawn between classes of participants that ought, and ought not, to participate in any particular kind of research, based on the ability of members of that class to bear burdens and on the appropriateness of placing further burdens on already burdened persons.

Injustice may arise from social, racial, sexual, and cultural biases. One special instance of injustice results from the involvement of vulnerable participants. Certain groups, such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized may continually be sought as research participants, owing to their ready availability in settings where research is conducted. Given their dependent status and their frequently compromised capacity for free consent, they should be protected against the danger of being involved in research solely for administrative convenience, or because they are easy to manipulate as a result of their illness or socioeconomic condition.

CONFIDENTIALITY

The steps in which researchers take to protect information collected from participants is known as assuring **confidentiality**. Individual information is protected through 1) HIPAA Privacy Ruling (see page 27), 2) assigning identification numbers, 3) storage of collected data in locked filing cabinets and 4) reporting only group data to the public.

Talking and sharing is a part of our culture. Sometimes there is conflict between research behavior and one's own personal behavior. In research, all individual data (facts, findings) are confidential; but in one's own personal activities, we may decide to share some things with others who are important to us. Because we want to give and share by our very own human nature, research training is essential. Since the research staff has many contacts, others may try to pry for information or attempt to get the research staff to reveal confidential information. The research team must be honest with inquiring individuals that the information collected is confidential. We may need to take on a role in assisting with research in addition to our main job or position. In order to maintain confidentiality, data collectors who are also community outreach staff may be assigned to collect data in a district other than their own.

EXAMPLE

. . . of a procedure to assure confidentiality in data collection: each outreach staff (data collector on the project) will be assigned to collect data in a service district where they are not the outreach provider. For example, on O'ahu, an Urban community outreach staff may be assigned to collect data in the Ko'olauloa district or a Ko'olaupoko community outreach staff will be assigned to collect data in Wai'anae, etc. Having the outreach staff collect data in another district may help participants to speak freely and in confidence.

SCENARIO: Community Outreach Staff collects data from Aunty P who lives in Lā'ie and her neighbor Ms. K participates in the study two days later. Ms. K asks the outreach worker what Aunty said.

What could the outreach worker do?

Answer: Do not disclose information to another participant and explain to the neighbor that information collected is private and confidential. Assure Aunty P that her answers will also be confidential and will not be shared.

RESEARCH REVIEW BOARDS

The "Institutional Review Board" (IRB) is a generic term to refer to a group whose function is to review research to assure the protection of the rights and welfare of the human subjects. Each institution may use whatever name it chooses.

An IRB is an appropriately constituted group that has been formally designated to review and monitor biomedical research involving human subjects. An IRB has the authority to approve, require modifications in (to secure approval), or disapprove research covered by the U.S. Department of Health and Human Services and Food and Drug Administration Protection of Human Subjects Regulations. This group review serves an important role in the protection of the rights and welfare of human research subjects.

The purpose of IRB review is to assure, both in advance and by periodic review, that appropriate steps are taken to protect the rights and welfare of humans and animals participating in the research. To accomplish this purpose, IRBs use a group process to review research protocols and related materials (e.g., informed consent documents and investigator brochures) to ensure protection of the rights and welfare of research participants.

Every institution engaged in human participant research conducted or supported by a Federal department or agency that has adopted the Common Rule (Federal Policy for the Protection of Human Subjects) is required to designate one or more IRBs under an assurance of compliance. Some other institutions may require research protocols to be authorized by a governing board, such as a board of directors or research committee.

The function of the institutional review board is to assure that the designs of studies are within the recognized standards of ethical conduct and provide an opportunity for ethical guidance and consultation:

- The risks to the participants are minimal in relation to the research being done. The research being done does not expose participants to unnecessary risk.
- The risks of the participants are reasonable in relation to anticipated benefits. The importance of knowledge gained is reasonable to the expected result.
- The selection of participants is specific to the study's goals

- The safety of vulnerable populations such as children, prisoners, pregnant women (the fetus), mentally disabled individuals, or economically or educational disadvantaged individuals
- There is consistency between the research being done and the setting
- Participants are informed and consent for participation is obtained
- The research protocol includes a plan for monitoring data collected to ensure safety of research participants
- The research information will be protected and kept confidential

Native Hawaiian Health Care Systems
Institutional Review Board (NHHCS IRB Report, 2004)

Papa Ola Lōkahi, in partnership with the five Native Hawaiian Health Care Systems [Hui No Ke Ola Pono (Maui); Na Pu'uwai (Moloka'i/Lana'i); Hui Mālama Ola Nā 'Ōiwi (Hawai'i); Ho'ola Lahui Hawai'i (Kaua'i); and Ke Ola Mamo (O'ahu)], established the Native Hawaiian Health Care Systems – Institutional Review Board or NHHCS-IRB in response to the increase of research in Native Hawaiian communities and the increase of Native Hawaiians conducting research. The NHHCS – IRB is registered with the federal Office of Human Research Protection and is staffed and administered by Papa Ola Lōkahi. This IRB has the following unique distinctions:

- It is a community-based IRB
- 40% of the membership are community representatives
- It has representatives from all the major islands
- 70% of the membership are of Native Hawaiian ancestry

As a part of the community research infrastructure, the NHHCS IRB takes an active role in addressing community and cultural concerns, incorporating cultural protocols in research, and reconciling cultural beliefs with scientific goals. This assures there is support for scientifically sound and relevant research. There are more members representing the community than is federally required on the NHHCS IRB. This balance ensures a community voice that can be achieved by the involvement of many members to cover all islands. The mix of members assures a thorough review of protocols.

The NHHCS IRB has provided Papa Ola Lōkahi and the Native Hawaiian Health Care Systems with a forum to discuss and shape research in Native Hawaiian communities. The benefit for participants is that research will be done in a manner that is respectful of the Native Hawaiian culture and communities.

Other Review Boards

The aim of a review board is to ensure that:

- The risks of scientific advancement shall never outweigh the value of human life
- Appropriate ethical conduct and regulatory compliance is maintained
- Respect for all persons is honored

Review Boards are forums to screen, review, and monitor research and researchers. The Boards offer protection of individuals/participants, groups and communities and ultimately lend support for scientifically sound and relevant research. The

TIP

Before collecting data, discuss your plans with the agency or organizational representative who is responsible for reviewing the project and giving approval.

Institutional Review Board is a part of the research infrastructure for institutions which receive federal funding. Institutions and agencies involved in research have their own institutional review board, or develop a consortium with other institutions and share a review board. Sometimes the name of the review board may be slightly different, such as the "Ethics Committee." For the University of Hawai'i, the Board is called the "Committee on Human Subjects." Some of the agencies and hospitals in Hawai'i have a joint review board, which means that the same board reviews protocols for a few agencies or institutions.

INFORMED CONSENT

The informed consent is a document that describes the project and is reviewed by the potential participant before participating in the research. Potential participants must understand the implications of participating in a research study. All individuals have the freedom to decide if they want to participate. The research team must make sure that participants understand the implications of participating. The informed consent must provide potential participants with adequate information about the research activity and assure them that participation is voluntary and the participant can stop participating at any time without negative consequences. A sample Consent Form is shown in the Appendix.

The informed consent document must:

- Provide the potential participant with sufficient information about participating the research study
- Assure the potential participant that participation is voluntary and can be withdrawn at any time without negative consequences
- Contain simple and understandable language

The Informed Consent Form must include:

- Title of the study.
- Names and addresses of personnel responsible for the study.
- An invitation to participate – not "requested" or "chosen" ("You are invited to participate in a research study").
- Clear description of the purpose of the study (do not use medical jargon).
- Detailed description of the procedures. Describe step-by-step what will occur and how much time will be required. Indicate if any part of the procedures are a part (always, sometimes, never) of the participant's standard care, and how much blood will be drawn if applicable.
- Potential risks to participants (psychological, social, and physical) and the steps that will be taken to protect against these risks, the likelihood of risk occurrence, severity, duration.
- Potential benefits of the study and indication if the benefits are directly for the participant or for others in general.
- Economic considerations such as, "Will participants have to pay for any thing as a result of participation?"
- Confidentiality and anonymity considerations – explain the steps taken to ensure confidentiality will be kept (not sharing of individual's information with others), who will have access to the data and when the data will be destroyed. Explain the steps taken to ensure that the participant will remain anonymous (no names, use code number).

"Assent for children" is an important concept to understand and implement.

- Freedom of participants to ask questions and stop participating in the study at any time without penalty.

Assent for Children under Age 18 Years

For children under the age of 18 years, an assent form is used. It is important to assure that the child freely agrees to participate in the research, and that their parent/guardian is not pressuring them to participate. A sample Assent Form is shown in the Appendix.

PROTECTION OF HEALTH INFORMATION

What Is HIPAA?

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule is the first comprehensive Federal protection for the privacy of personal health information. Research organizations and researchers may or may not be covered by the HIPAA Privacy Rule.

HIPAA was established in response to:

1. The lack of standardized collection, storage, and transmission of health data
2. The increasing health care cost and
3. The lack of privacy of individual health information or protected health information (PHI)

The privacy ruling protects the way health information is used and disclosed.

Why Should Researchers Be Aware of the Privacy Rule?

The Privacy Rule regulates the way certain health care groups, organizations, or businesses, called covered entities under the Rule, handle the individually identifiable health information known as protected health information (PHI).

Researchers should be aware of the Privacy Rule because it establishes the conditions under which covered entities can use or disclose PHI for many purposes, including for research. Although not all researchers will have to comply with the Privacy Rule, the manner in which the Rule protects PHI could affect certain aspects of research.

It is important to understand that many research organizations that handle individually identifiable health information will not have to comply with the Privacy Rule because they will not be covered entities. Compliance with the Privacy Rule is required on and after April 14, 2003, for most covered entities.

To Whom Does the Privacy Rule Apply?

The Privacy Rule applies only to covered entities, which are three basic groups of individual or corporate entities: health plans, health care providers, and health care clearinghouses.

Many organizations that use, collect, access, and disclose individually identifiable health information are not covered entities, The Privacy Rule does not apply to research; it applies to covered entities, which researchers may or may not be. The Privacy Rule may affect researchers because it may affect their access to information. To gain access for research purposes to PHI created or maintained by covered entities, the researcher may have to provide supporting documentation on which the covered entity may rely in meeting the requirements, conditions, and limitations of the Privacy Rule.

What Health Information Is Protected by the Privacy Rule?

The Privacy Rule defines PHI as individually identifiable health information, held or maintained by a covered entity or its business associates acting for the covered entity that is transmitted or maintained in any form or medium (including the individually identifiable health information of non-U.S. citizens). This includes identifiable demographic and other information relating to the past, present, or future physical or mental health or condition of an individual, or the provision or payment of health care to an individual that is created or received by a health care provider, health plan, employer, or health care clearinghouse. For purposes of the Privacy Rule, genetic information is considered to be health information.

The Privacy Ruling (as of April 14, 2003)

$$
\begin{array}{c}
\text{Access to} \\
\text{participant's} \\
\text{protected} \\
\text{health} \\
\text{information} \\
\text{for research}
\end{array}
=
\begin{array}{c}
\text{IRB} \\
\text{approved} \\
\text{Consent} \\
\text{Form or} \\
\text{Waiver of} \\
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\text{Authorization} \\
\text{or Waiver of} \\
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How Can Covered Entities Use and Disclose Protected Health Information for Research?

De-identified health information, as described in the Privacy Rule, is not protected health information and thus is not protected by the Privacy Rule. Protected Health Information may be used and disclosed for research with an individual's written permission in the form of an Authorization.

Protected Health Information may be used and disclosed for research without an Authorization in limited circumstances: (1) under a waiver of the Authorization requirement, as a limited data set with a data use agreement preparatory to research, and (2) for research on decedents' information.

De-Identifying Protected Health Information under the Privacy Rule

Covered entities may use or disclose health information that is de-identified without restriction under the Privacy Rule. Covered entities seeking to release this health information must determine that the information has been de-identified using either statistical verification of de-identification or by removing certain pieces of information from each record as specified in the Privacy Rule.

The Privacy Rule allows a covered entity to de-identify data by removing all 18 elements that could be used to identify the individual or the individual's relatives, employers, or household members; these elements are enumerated in the Privacy Rule. The covered entity also must have no actual knowledge that the remaining information could be used alone or in combination with other information to identify the individual who is the participant of the information.

Since 2003, HIPAA safeguards an individual's privacy. It has always been the responsibility of the research team to safeguard the participants' privacy and confidence.

Under the Privacy Rule, the identifiers that must be removed are the following:

1. Names
2. All geographic subdivisions smaller than a state, including street address, city, county, precinct, ZIP Code, and their equivalent geographical codes, except for the initial three digits of a ZIP Code if, according to the current publicly available data from the Bureau of the Census:
   a. The geographic unit formed by combining all ZIP Codes with the same three initial digits contains more than 20,000 people
   b. The initial three digits of a ZIP Code for all such geographic units containing 20,000 or fewer people are changed to 000
3. All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death; and all ages over 89 may be aggregated into a single category of age 90 or older
4. Telephone numbers
5. Facsimile numbers
6. Electronic mail addresses
7. Social security numbers
8. Medical record numbers
9. Health plan beneficiary numbers
10. Account numbers
11. Certificate/license numbers
12. Vehicle identifiers and serial numbers, including license plate numbers
13. Device identifiers and serial numbers
14. Web universal resource locators (URLs)
15. Internet protocol (IP) address numbers
16. Biometric identifiers, including fingerprints and voiceprints
17. Full-face photographic images and any comparable images
18. Any other unique identifying number, characteristic, or code, unless other wise permitted by the Privacy Rule for re-identification

Authorization for Research Uses and Disclosures

One way the Privacy Rule protects the privacy of PHI is by generally giving individuals the opportunity to agree to the uses and disclosures of their PHI by signing an Authorization form for uses and disclosures not otherwise permitted by the Rule.

The Privacy Rule establishes the right of an individual, such as a research participant, to authorize a covered entity to use and disclose his/her PHI for research purposes. This requirement is in addition to the informed consent to participate in research.

The Privacy Rule was not intended to impede research. Rather, it provides ways to access vital information needed for research in a manner that protects the privacy of the research participant. The Privacy Rule describes methods to de-identify health information such that it is no longer PHI or governed by the Rule. If de-identified health information cannot be used for research, covered entities can obtain the individual's written permission for the research in an Authorization document describing the research uses and disclosures of PHI and the rights of the research participant. When obtaining the Authorization form is not practicable, an IRB or Privacy Board could waive or alter the Authorization requirement. The Privacy Rule also

TIP

Exclude the following from a limited data set:
- *Name*
- *Street Address*
- *Telephone and Fax Numbers*
- *E-mail Address*
- *Social Security Number*
- *Certificates and License Numbers*
- *URLs and IP addresses*

Consent provides individuals with information regarding research and enables the individual to decide whether or not to participate or decline participation in a research study.

*An **authorization** is an individual's written permission to allow the use and/or disclosure of Protected Health Information for a particular purpose. An authorization is needed for research use and/or disclosures*

provides alternatives to obtaining an Authorization or a waiver or an alteration of this requirement, such as limited data sets or with representations provided for certain research activities. The Privacy Rule also contains a provision that "grandfathers" research that is ongoing before the compliance date to facilitate compliance with the Rule.

The Do's and the Don'ts

CAN do research with IRB approval or waiver of authorization to:

- Build a database of patient information
- Access and use patient identifiable information as approved by IRB
- Do a public presentation or publish findings using aggregate or de-identified information.

CANNOT do research in these situations:

- Any research without IRB approval or waiver
- Publish or publicly present findings that identify the patient without patient authorization
- Access and collect patient data in preparation for a research project

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SCENARIO #1: My supervisor has asked me to interview 100 clients at our clinic to determine how their keiki's (child's) diabetes has affected their family.

Do I need IRB approval?

Answers:

Yes – for research. If you or your supervisor intends to publicize, publish or share the data you collected with others and do not get a patient authorization or an IRB approval or waiver you would be violating the clients' rights.

No – for service provision or quality assurance. If you intend to change or improve the outreach protocol for families of children with diabetes and need to evaluate the quality of your current services you can do so without IRB waiver or approval.

SCENARIO #2: We will be collecting data from participants at a community health fair. None of the team are hospital employees. The project directors do intend to publish the results of our data collection.

What approvals does the project need?

Answers:

If this is a research activity, and your agency intends to publicize, publish or use the data you collected for any other purpose and do not get a patient authorization

or an IRB approval or waiver you would be violating the clients' rights. The project would need to have Institutional Review Board(s) approval and a HIPAA waiver.

If the project is collecting data for quality improvement and there is no intention to publish, then you do not need an IRB approval or waiver. Quality improvement means that you're collecting the data to improve the services your agency is providing. The team must destroy the database upon completion.

SCENARIO #3: I am told to recruit participants for a study about Diabetes and Self-Awareness. Since I am working with several community groups, I am planning to ask the participants in each group to give me the names and contact information of their friends and family members who have diabetes.

Is this okay to do this way?

Answer: No. Individual's identities are confidential. Prior to contacting a potential participant, we must get the individual to say it's OK to contact them. Friends and family cannot release the participant's identifying information. The legal caregiver must release the information if the participant is a minor (child less than 18 years old).

Strategy to Use: Once when the study has been approved by the Review Boards, it is okay to give out fliers about the Diabetes Study and ask the community group members to give the flier to someone they know who has diabetes. Then it's up to the person receiving the flier to contact the Study.

SCENARIO #4: I need to collect data from the parent AND the child. The parent has consented to participating in this Project already.

Can I start collecting data from the child?

Answer: Wait! Have you obtained assent from the child?

Strategy to Use: Once the parent consents to participate, you'll need to obtain assent from the child (ages 6-18 years). If the child is age 18 or older, they will also need to consent to Project participation. Some research review boards extend the child's age to 21 years.

SCENARIO #5: The parent does not give consent but the child wants to participate in the research project.

Can I give the surveys to the child to answer even if their parent declines to participate in the project?

Answer: No. Although the child is willing to assent, the child cannot participate without a parental consent.

Researchable issues come from a variety of sources. The most meaningful ones are usually those from the community's own experiences.

Strategy to Use: Once the parent consents to participate, you'll need to obtain assent from the child (ages 6-18 years). If the child is age 18 or older, they will also need to consent to Project participation.

SCENARIO #6: The research protocol requires both the parent and child to participate in the study.

What happens if the parent agrees to participate in the study and the child does not want to participate?

Answer: In order to respect the child's choice, you spend the allocated amount of time with the child, but you do not ask any research questions.

Strategy to Use: Have the child do something else in lieu of filling out the research forms.

SCENARIO #7: I have finished collecting data from both the parent and the child.

What happens if the parent asks you what their child said on the child's research forms?

Answer: Information collected from any participant is considered confidential and therefore sharing such information would be a breach of confidentiality.

Strategy to Use: Explain that everyone's answers are confidential.

SUMMARY

Ethical conduct is important to maintain in a research project. There have been times in history that researchers treated the participants unethically. The informed consent process assures that participants understand the implications of their participation in research studies. Children under age 18 are required to sign an assent form. Research review boards have been established to assure participants are treated with dignity and respect. According to the privacy rule, any health information which can cause us to identify the participant cannot be transmitted or collected without the individual's permission. Individuals must be given the opportunity to agree to the uses and disclosures of their protected health information.

PART IV:
KEYS TO PROJECT SUCCESS

OVERVIEW

This section will describe the keys to the making of a successful project. The pre-planning phase is one of the most important phases. Understanding team roles is also important because the roles may be shared on a research project. Since projects move along better if all members of the team consistently do things the same way, research supervision will be described.

OBJECTIVES

1. Describe the activities which occur in the pre-planning phase.
2. Describe team roles and supervision.

A PRE-PLANNING PHASE

The choices the research team makes about the work they do is important and powerful. A pre-planning phase is necessary for any project. The pre-planning phase is especially important in situations where a partnership is forming between the academic researcher and the community partners because individuals come from different orientations (beliefs and experiences). The pre-planning phase has several phases:

- Decide what is the topic
- Decide who will constitute the partnership and who are the players
- Consider the money-time commitment
- Determine who is the advisory
- Determine how to pretest the plan

What Is The Topic?
Topic clarification is very important. All individuals have vested interests and biases. Topics that are too broad cannot be successfully researched. Topics must be significant to the participants, realistic and understandable, and must lend themselves to taking action at a later stage. Research project ideas must be specific so the actions can be performed.

Who Will Constitute The Partnership and Who Are The Players (Participants)?
Every community-oriented participatory research project will have a different array of partnership members and participants. Those with vested interests are called "stakeholders." The stakeholders are determined according to level of interest and experience on a research topic, the feasibility of how many individuals can work together in a group and the length of time the group has to work on the project.

We recommend that the individuals on the partnership work together to write the proposal (protocol) as a group. This is important because all members will have to develop a common understanding to implement the project.

The Money-Time Commitment

The project may start out with excitement and volunteerism, but over time, interest will decrease. Alternatively, the work load and commitments may increase. We believe in equity among the individuals on the research team. If monetary compensation is available, all individuals need to receive it for their efforts. Job descriptions are needed for all team members to help guide the amount of involvement and compensation. A community-oriented team may wish to maintain the balance of power such that the ratio of community members was twice as many as the academic researchers. Project budgets are openly and jointly reviewed by the core team. A project timeline is developed by the entire team so all members have input and gain understanding of project responsibilities and commitments.

Who Will Be On the Advisory?

The project advisory will shape the project design and implementation, and will determine the reliability of the findings. Advisory members may also "pave the way" in the community for the project to run. They may review the results and work with the team to assure acceptability of the presentation of the findings.

How to Pretest the Plan?

Many ideas look great on paper. The entire research plan (proposal) needs to be field tested for feasibility, time commitments and problems in the methods. In order to pretest the protocol, the project will need individuals who are willing to serve as "pretesting consultants." Select 4-6 individuals who are willing to go through the protocol and are also willing to give feedback and consultation on what worked, what was confusing, and how things can be improved. Prior to pretesting, the protocol may require the review of an ethics committee, depending on the topic.

SCENARIO: You are interested in helping out to collect the data on a new community-oriented research project. In attending the pre-planning meetings, it seems that each lead member of the research team has a different idea about what needs to be studied. Everyone is busy trying to "sell" his or her idea at the meetings.

What could you do to facilitate the team's situation?

Answer: Respectfully point your observation and confusion and recognize that there are many good ideas but it will not be possible to do all of them at once. For example, ask if the group could possibly move some of the ideas under broad categories, or prioritize them. If you are noticing the confusion, chances are that others notice it too, but have not said anything. The team members may begin to feel frustrated and lose interest. Everyone counts on the team -- everyone can be a catalyst for each other.

Kukākukā or to talk over with participants gives everyone a better understanding of their role in the project.

TEAM ROLES AND SUPERVISION

Roles on a Research Project

Projects and research studies benefit from team involvement. A group of committed and collaborative individuals working together will be able to plan, implement and evaluate a study or project that fits the needs of the community.

There are many roles on a project or research study:

Role	Responsibility
• Recruiter	Seeks out community participants
• Interviewer and/or Data Collector	Conducts "talk story" sessions with a participant and/or gathers data
• Computer Specialist	Manages the computer systems, design online data entry forms, create project web site
• Data Analyst	Tabulates the data that was collected
• Project Coordinator	Provides supervision and support to the research team
• Community Spokesperson	Represents information to the community, assists with public relations
• Research Assistant	Assists to manage the daily aspects of the project
• Co-Investigators (Co-I)	Monitors the daily operations of the project and assists the principal investigator
• Principal Investigator (PI)	Responsible for all aspects of the project
• Fiscal Manager	Manages the project budget and expenditures
• Consultant	Provides specialized skills or knowledge and guides the project
• Other Roles	Every project has different needs and may require other roles

" 'a'ohe hana nui ke alu 'ia." No task is too big if done by all. Every role in a research project is important.

EXAMPLE

Roles may be shared on a research project. One individual may take on more than one role: they may be the recruiter, data collector and community spokesperson.

Research Supervision

The entire team on a project or research study must do things the same way. Doing things the same way is called standardization.

Unstandardized activities may affect the quality of the project's results and bias the data. Since each of us come from different backgrounds and have different experiences, we may have different ways of doing the same thing. Achieving standardization of our research skills will require practicing and supervision.

There are many different strategies to provide training for participating in a research project. Most often more than one strategy is used to provide training. Different supervision strategies fit the preferences of different individuals. One training format will not fit all learners. The most common ones are:

- Discussion: participating in a classroom style discussion with PowerPoint slide presentation
- Experiential: role playing an interview and data collection session
- Audio-visual: watching a training video with common problematic research situations, followed by discussion of the vignettes
- Reading: reading textbooks, project manuals and looking up information
- Discussion: (Informal) joining staff get-togethers over lunches and (Formal) meeting with your supervisor
- Feedback: receiving suggestions and comments from your supervisor and peers

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SCENARIO: I have many years of experience working in the community. I've made home visits for the past 5 years. The activities in this research project seem no different from the other times I've made home visits to collect information.

Why do I need "supervision"?

Answer: Research supervision is an opportunity to enhance your professional growth and a time for project staff to give comments and suggestions with the other project personnel. Your experiences will help to shape the Project so we will need to coordinate your experiences into standardized activities; the entire team will do things in the same sequence. Otherwise, it may affect the results.

SUMMARY

The preplanning phase sets the stage for the project. In the preplanning phase, decisions are made about what is the topic, who will constitute the partnership, the money-time commitment, who will be on the advisory and how to pretest the plan. Community-oriented participatory research projects benefit from team involvement. Roles may be shared and an individual may be called upon to take on more than one role. Research supervision is one way to provide training for the entire team. Supervision is needed in order to standardize the way things are done on a project.

PART V:
RESEARCH TOOLBOX

OVERVIEW

This section is about actually doing the data collection. It will describe commonly used data collection tools and techniques for interviewing and asking questions. Common data collection situations and solutions are discussed.

OBJECTIVES

1. Describe data collection.
2. Describe commonly used data collection tools.
3. Summarize techniques for interviewing and use of questions.
4. Identify common data collection situations and solutions.

WHAT IS DATA COLLECTION?

In a research project, all of the data is collected using the same process for each participant. This way, we can be sure that what we learn from our project is truly because of differences among the participants rather than differences in how we collected the data (or treated the participants). Data collection is the process by which we invite participants to share their view with us and collect information needed to answer the research issue. The project directors are responsible to develop step-by-step guides to manage the data collection.

In general, the following information is needed to guide in data collection:

- Which data to collect
- How to collect the data
- Who to collect the data from
- Where to collect the data
- When to collect the data

COMMONLY USED DATA COLLECTION TOOLS

Surveys and Interviews
Surveys and interviews give the participant opportunities to share their thoughts and ideas with us. This will give us an opportunity to learn from the participant. The goal in community-oriented participatory research is to learn from the participants so we can improve the quality of our actions.

There are three words that are often used to describe talking with individuals and groups to gather verbal information:

- **A survey** (questionnaire) is a fixed arrangement of questions in a meaningful order. Surveys help us describe how participants see a particular issue or idea. For example, we can ask participants to fill out a survey to show how much they agree or disagree with an issue. Surveys may be administered in person, with a paper-and-pencil format, orally (e.g., over the phone) or mailed.

Each data collection session involves a unique interaction between the data collector and the participant

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- **An interview** (talk story) may consist of a fixed arrangement of questions or the questions may be less fixed in their arrangement. Interviews also help us describe how participants see a particular issue or idea. For example, we can ask participants to participate in an interview to tell us about what they think about something.
- **A focus group** is an interview that is performed with a group. The group leader has to take into account the group dynamics (how the individuals act with each other) because the group's interactions will impact the results of the focus group interview. There are usually 6-10 participants in the group.

Surveys (questionnaires) and interviews are the most commonly used data collection methods. In an interview (talk story), the interviewer asks the questions. Questions may be either closed-ended or open-ended. Closed-ended questions allow the participant to choose an answer from a predetermined list of responses. Open-ended questions allow the participant to respond in their own words.

Advantages and disadvantages of surveys and interviews:

Advantages: Surveys and Interviews	Disadvantages: Surveys and Interviews
Surveys (questionnaires) are easier to administer. A written survey or interview offers the possibility of the participants' anonymity. Interviews can be used with most participants because the data collector can observe how participants respond to the questions and ask more questions to clarify.	The participant must be able to read, write and understand the survey or questionnaire in order to fill it out. Interviews need much more time and cannot offer participants anonymity. The data collector must try to be non-judgmental and encourage the participants' honest responses. The data collector must be aware of their non-verbal and facial expressions to the participant's responses.

Rating Scales

A scale is commonly used to collect data by asking participants to rate something according to categories. Scales are useful to gather information about attitudes and values. Scales are designed in many different formats.

Use of a rating scale may provide participants' answers quickly. However, there may be times that the questions on the rating scale do not adequately depict (match) the participant's viewpoint about a situation.

TIP

Topics that are personal in nature are better handled with an individual interview rather than a focus group interview.

On a rating scale, the participant may be forced to select a number that "best represents" his or her real-life answer. At times, the participant's real life answer may fall between two numbers. For example, if "1" means "very good" and "2" means "fairly good", the participant may want to answer half way between "1" and "2" to indicate "somewhat very good, but not all the time." If a rating scale is used, the instructions should indicate that the participant should select the "best" answer from the choices given.

Advantages and disadvantages of rating scales:

Advantages: Rating Scales	Disadvantages: Rating Scales
Scales are an efficient way to measure how the participant feels about a topic. Scales can be administered orally or in writing. Scales are generally faster than interviews to administer. Scales are more easily scored or summarized.	Participants answer scales based on how they think we want them to answer. This is called "social desirability." Participants may have the tendency to express an attitude at the extreme (such as strongly agree) at all times instead of selecting other answers. The participant may have a tendency to always agree with statements regardless of the content.

TECHNIQUES: SURVEYS AND RATING SCALES

Administering a Survey (Questionnaire)

Often the participant has to indicate a rating for their answer on a survey. For example, we may ask the participant, "On a scale from "1" (strongly Agree) to "5" (Strongly Disagree), how boring do you think your life is?"

This is an example of a printed survey →

I THINK MY LIFE IS BORING:

1. Strongly Agree
2. Agree
3. Undecided
4. Disagree
5. Strongly Disagree

Sometimes it may be hard for a participant to focus on the question and remember the answer choices. If the question and answer choices were read aloud to the participant, they would need to remember all of the choices in order to give an accurate answer. In addition, the participant may become distracted or may not be listening to you too much. On the other hand, if the participant is reading, he/she may have difficulty reading the words of the questions. In order to assist in this situation, it may be necessary to read the question for the participant.

The Answer Card Method: A Participant-Friendly Approach

An answer card may help the participant keep their focus. The advantage of using an answer card is that the participant can respond by pointing to the answer. This is useful with both children and adults.

The following steps show the Answer Card Method:

1. The data collector reads the question: **"I THINK MY LIFE IS BORING"**
2. The participant is shown the response card and asked to show (point to) their answer:

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(SAMPLE RESPONSE CARD)
1. **Strongly Agree**
2. **Agree**
3. **Undecided**
4. **Disagree**
5. **Strongly Disagree**

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3. The data collector then records the answer.
4. The data collector then reads the next question and again the participant indicates their answer.

PRACTICE:

Here is a survey that has 4 questions. The answer choices are: "1" Strongly Agree; "2" Agree; "3" Undecided; "4" Disagree; "5" Strongly Disagree.

Survey Questions:	Response
1. I am a healthy person	
2. I make it a priority to get lots of exercise	
3. I eat a healthy diet	
4. I like to eat fast foods	

Trial #1: (Oral administration) Read the answer choices to your partner out loud. Next, tell them you will be asking for their answer on 4 questions. Read each question and ask the person for their answer.

Trial #2: Use the "Response Card" (shown below). Request that the participant look at the "card" to help focus, or to point to their answers. The participant may also say the answer aloud if they desire.

> (RESPONSE CARD)
> 1. **Strongly Agree**
> 2. **Agree**
> 3. **Undecided**
> 4. **Disagree**
> 5. **Strongly Disagree**

Discussion:

- Which method was generally easier?
  (It depends on the person you're working with)
- Which method may work out better for an 8 year old child?
  (Using the response card – young children have a hard time remembering the answer choices)
- Which method may work out better if you are giving the survey to your co-worker?
  (If your co-worker can pay attention to the answer choices, there is no need to use the response card)
- Which method may work out better if the environment was distracting and noisy?
  (The response card will assist the participant to focus on the questions you are asking)

TECHNIQUES: INTERVIEWING (TALKING)

General Techniques for an Interview

An interview is talking story with a purpose. The themes and major ideas from each participant's interviews will be categorized together to create a story that represents a group of individuals. A "Focus Group" interview is an interview that is conducted with a group of participants instead of one person. Interviews and focus groups give us opportunity to learn from the participants.

Pacing the Interview. Sometimes interviewers tend to rush through an interview because they sense either the participant is getting impatient or the interviewer is getting impatient. Make sure the participant finishes their answer before the next question is asked. "I'll stop for a moment . . ."

Focusing the Interview. Stay on track. Sometimes the participant will get side tracked and start to talk about something else. Recognize that what the participant says is important and then gently guide the participant back to the question. "So we were talking about . . ."

Maintaining Accuracy of the Questions. Find out what the reason is for asking a certain question. Asking the questions as they are worded is very hard to do, yet this

may be important. The interview will work out the best if you have an idea about the focus of the question. *"I'd really be interested in . . . (repeat the question) . . ."*

Probing. The goal of the interview is to get the participant to answer the questions with responses that fit the answer categories. If the answer is not clear, or does not fully give the details, you will need to probe for the rest of the answer. Probing is a technique which allows the interviewer to expand the discussion and follow up on a topic.

The key to good probing is to listen carefully to the participant's attempts to provide the appropriate response:

- First, repeat the question
- Then, use techniques for asking "open questions" (see previous pages) "Can you tell me more about that?"

Figure Out What "Don't Know" Means. "I don't know" may mean many different things. For example:

1. Really does not know
2. Cannot make up their mind
3. Does not understand the meaning of the question.
4. The question is not applicable
5. Is embarrassed to answer
6. Does not understand the directions
7. Does not understand the meaning of the words in the question
8. Too busy to spend time thinking about the answers etc.!

All about Active Communication

Active communication is a skill. Like all skills, it requires practice to develop. The interview can become biased without active listening.

Paraphrasing. Reflecting in one's own words the essence of what the speaker has said. This is the most useful listening skill in that it demonstrates one's commitment to understanding.

How to paraphrase

- Keep the focus on the speaker. "So you felt…", "You're saying…", "You believe…"
- Re-state in your own words, rather than simply parroting the speaker.
- Reflect both *content and feeling* whenever possible and appropriate.
- Be brief, much briefer than the speaker.
- Match to some extent the emotional intensity of the speaker in your paraphrase.

Why paraphrase?

- Demonstrates understanding and/or the attempt to understand.
- Clarifies the communication. (If you misunderstand, they'll correct you.)
- Affirms worth of speaker and encourages them to say more.
- Reduces defensiveness of both you and the speaker.
- Slows down a fast or angry conversation, helping to reduce the intensity of the conflict.

Examples (paraphrasing)
- "So you were really frightened when . . . "
- "You felt I was being unfair to you when . . ."
- "Let me make sure I understand you. You're saying you don't want that responsibility . . . "

Openness. Openness is a way of communicating to encourage receiving more information about the perceptions and needs of others, even if those may be critical or competitive. This is often important in order to clarify the situation before attempting to respond.

Examples (openness)
- "Say more about . . ."
- "Spell that out further. . . "
- "Tell me what you have in mind . . . "
- "Give me a specific example . . . "

Agreement Stating. Agreement stating is a way of acknowledging where one agrees with others. During the data collection process, agreement stating is not used too much because it can bias the participant to think that the data collection is "on their side". Rather, the data collector remains neutral and reports what the participant tells them. However, agreement stating is often used as a way to break the ice and get started talking. For example, the data collector may say "I agree with you that there is always road construction especially when you're running late. . ."

Examples (agreement stating)
- "I agree with you that . . . "
- "I can see what you're saying about . . . "
- "I share your concerns about . . . "

USE OF QUESTIONS

Types of Questions
Closed questions are restrictive in nature. They limit the options available to the person for responding 'yes', 'no', 'maybe', or 'I don't know.' This type of question can help to focus on a specific piece of information or attempt to clarify a point. However, it can also encourage defensiveness, implying that a 'right' answer exists or push someone into a position.

Open questions are broad in nature. This type of question gives considerable freedom to the person being asked to determine what his/her response will be. They open the door to future discussion. Use open questions to encourage the responder to expand on, describe their experience, and invite exploration.

In most Pacific Island cultures, it is considered rude to ask too many questions. Thus a thorough explanation will allow Maopopo pono or a correct understanding of the interviewing process.

Examples: Closed Questions	Examples: Open Questions
• "Don't you think we should wait?" • "Are you planning to quit then?" • "Do you have enough information to make a decision?" • "Aren't you even going to try?" • "Do you understand what I mean?" • "Do you understand that the contract is unclear?" • "Have you noticed low morale with your other staff?" • "Don't you think this is basically a financial problem?"	• "What does 'fair' mean to you?" • "What did I do that gave you the impression I'm irresponsible?" • "How did the phone call affect you?" • "What's that like for you?" • "What do you think I'm saying?" • "What do you think about the clarity of the contract?" • "How would you describe the morale of your other staff?" • "What do you think is at the root of this problem?"

Understanding a process is good, but understanding the intent and reason allows for more open communication.

Asking the Right Question

Opening questions help to start a **conversation:**

- Could you tell us the concerns that brought you here today?
- Please explain to us what has been happening.
- Can you give us some background?
- Tell us your view of the situation.

The following questions are used to get **information:**

- Can you give me an example?
- Could you tell me more about how you view _____?
- Can you explain _____?
- Can you help me understand why_____?
- Could you describe what happened when_____?

The following questions help get at **interests:**

- What is important to you?
- Can you help me understand why that's important?
- What concerns you about the situation?
- How does _____ affect you?
- _____ matters to you a lot - is that right?
- Is there something you think that [other party] doesn't understand about your situation?

These questions will help to get at **solutions:**

> - What might work for you?
> - What can you do to help resolve this issue?
> - What other things might you try?
> - What would make this idea work better for you?
> - Is there some way we can meet both X's need for __ and Y's need for __?

These questions will get at **consequences:**

> - Are you planning to move? (get another job . . .)
> - What problems might there be with this idea?
> - If you agree to this solution and _____ happens, then what?
> - What other options do you have if you don't do it today?

These questions will test for **agreement:**

> - Is this agreement acceptable to everybody?
> - Have we covered everything?
> - Is there any piece of this you're uneasy with?
> - Now, is this what you're agreeing to:_____?
> - Can you live with this everyday, every week from now on?

Nonverbal or Other Prompts

Help a participant to continue with their answering. Make sure the prompts that you use are neutral so it will not bias the interview. For example, do not use prompts that show your agreement or disagreement with the participants' answer. (Do not use prompts such as: "Way to go!" or "right on!")

PRACTICE:

Ask your partner to tell you about something that recently happened to them.

Trial #1: Ask your partner to "just talk" and do not say anything during this time. Just continue to look at your partner in the face.

Trial #2: Try using several probes and non-verbal prompts.

Discussion: it is hard to talk without getting feedback from the listener. Verbal or nonverbal prompts indicate the listener's interest and shows that the message has been heard. However, too many verbal or nonverbal prompts may distract the participant and they may stop talking. The amount of verbal and nonverbal prompts depends on the personal style of the interviewer and participant.

If we listen and ask questions, individuals will teach us a lot; the participants of our research are the experts.

TIP

Some useful prompts:
- *a nod of your head*
- *an interested look*
- *uh huh*
- *go on*
- *I see*
- *Silence (look interested, give the participant a few moments)*

COMMON DATA COLLECTION SITUATIONS AND SOLUTIONS

In this next section, several common data collection situations will be reviewed. Suggestions are provided on what the data collector could do. Each data collection situation is different and unique. Each situation will require active listening and creativity.

The Tangent
Participant deviates from the question and begins to talk about an unrelated topic.
What to do: Stop participant (gentle interruption) and acknowledge the tone of what is being said. Quickly refocus the individual onto the next question.

Participant Answers with One Word throughout the Interview
Participant responds with one word answers such as "yes", "no" or "ok" to all questions.
What to do:

- Refocus or rephrase question, using prompts. Talk story in a way to make it more interesting.
- Display genuine interest to show that you want to find out more.

Participant Makes Complaints
Participant responds with complaints about situation.
What to do: Stop participant (gentle interruption) and acknowledge the tone of what is being said. Paraphrase what the participant stated. Quickly refocus the individual onto the next question. Rephrase the question. Ask the questions so your flow is more animated, thus keeping the participant's attention to the topic.

Participant Decides Not To Participate
Participant refuses to participate or changes their mind about participation.
What to do: Re-explain the Project. Offer options such as an opportunity to reschedule. Make sure participant will not feel like they have "let you down."

- Offer to reschedule; give participant your business card and review the contact number for office.
- Ask if participant would like to speak to someone who is in charge of the Project.
- Provide a follow-up phone contact.

Data Collector Is Not Prepared
For example, the data collector forgets supplies and arrives to the participant's home, not organized, or brings the wrong supplies . . .
What to do:

- Allow yourself enough time to prepare. Create a "data collection materials" checklist and review it prior to leaving the office and prior to entering the data collection location.
- Before you leave the office, make sure you have all the paperwork in sequential order and equipment available.
- Let participant know you will need some time to set up paperwork and recorder.

The Data Collector Is Not Focused

The data collector or research participant is not "present" at the data collection session and questions are unfocussed.

What to do: Determine what is comfortable in terms of eye contact for your participant; match your eye contact with that of the participant.

- Use eye contact to draw the participant back into the data collection session/questions. The amount of eye contact may change within the data collection process, according to the tone.
- Sit up and lean towards direction of the participant.
- Avoid clicking of pen, or fidgeting or playing with objects.

Data Collector Is a "Klutz"

Ever have one of those days? The data collector drops tape recorder, fidgets with it while it is on, and is uncertain how to operate the device, tape runs out . . . and then knocks over the glass of water . . .

What to do: Practice makes perfect. Envision how you intend to set up the data collection environment. Anticipate problems which may occur. If something should occur, lightly "blame" yourself. Sometimes a participant may think it is their fault, such as the limited space on the dinner table and so forth.

- Compose yourself (count to "3").
- Make sure to reorganize paperwork and equipment prior to restarting the data collection. Things will happen but with preparation you will avoid unnecessary situations.

Data Collector Provides Counseling during the Session

Data collector tries to counsel and provide a service.

What to do: in a research role, the interviewer is not to provide a service.

- Acknowledge the tone of what's being said and refocus the interview.
- Be supportive, but neutral.
- Using a blank sheet of paper from your note pad, write down concerns or issues the participant introduces. State that after the interview is finished you will pass the participant's questions on to your supervisor. Some agencies also provide a "Service Request Form" that can be given to participants at the end of the data collection session.

Data Collector Manages the Interview by Taking Notes

At times note taking is okay, for example, if the data collector needs to write down a few thoughts. It is recommended that the data collector use a recording device to obtain an unbiased view of the participant's response. The only information that we write down is what we interpret. However, what we hear and interpret may not be exactly what the participant is telling us.

What to do: The data collector has forgotten the tape recorder or the batteries are dead. Reschedule the interview. When we take notes, we end up writing down our interpretation rather than what the participant is telling us.

We are human; our perception and biases will affect our note taking. We will only hear portions of the individual's story and miss the rest.

Distractions

Sometimes there is a lot of noise or activities in the area where the data collection is occurring.

What to do:

- Remind participant about the data collection time requirements before the data collection is started. Know when to be flexible and negotiate time. We are never sure when situations will arise with the participant.
- Try to negotiate with participant to continue the data collection session.
- Data collector should stay focused on the data collection activity; minimize looking in the direction of the distraction.
- For emergency situations, reschedule the data collection within 2-3 days.
- For non-emergency situations, let participant know allotted or remaining time and try to negotiate to continue with the current session. Rescheduling the interview will break the "flow" of the discussion.

Data Collector Acts Inconsiderate

Sometimes we may get too focused on their task. If this happens, the data collector gets upset at loss of control over the situation.

What to do: Interruptions are a part of every-day life and should be acknowledged. For example, if the family pet walks in, instead of being inconsiderate and shooing it away, find out the pet's name. Be patient, gently let child know pet can sit beside them. If pet becomes a distraction negotiate a deal with child. Let the child know that if pet starts to get bored, it may need to go into the next room.

SCENARIO: You arrive to an interview and as you enter the participant's home, you trip over a child's toy. The participant begins to apologize for the toy being in the way.

What could you say or do?

Answer:

1. Recompose yourself. Don't move the toy. Leave the toy exactly where it is, just be more vigilant and remember it's on the floor.
2. Apologize for tripping over the toy.
3. Blame yourself for not seeing the toy on the floor as you entered.
4. Don't dwell on this incident; redirect the participant to some other topic. Give the participant a compliment about something you noticed in the room – e.g., "Oh how cute! Your placements – did you make them?").

PRACTICE:

Assign roles as an Interviewer or Participant (to be interviewed). Switch roles for each scenario. For each scenario, use the following interview questions.

> **Interview Questions:**
> - What is your favorite thing to do and why?
> - What can you do to make more time for doing your favorite thing?

Scenario #1: (I don't know)

Participant to be interviewed starts out by answering "I don't know" to the questions. See if the interviewer can make you feel comfortable enough to give more information.

Scenario #2: (one word answers)

Participant to be interviewed answers in "one-word" answers (yes, no, dunno) and does not say more. See if the interviewer can help you be more expressive.

Scenario #3: (side tracked)

Participant to be interviewed starts out by not answering the first question and starts to talk about something else (example: "you know, one time I started this new job . . ." – explain in great detail the job). See if the interviewer can redirect you back to the interview.

Scenario #4: (inconsiderate)

Interviewer should roll their eyes at what the participant is saying, look bored, look at watch, play with pen, check for messages on cell phone, etc. How did those actions make you feel as the participant who is trying to tell your story?

SUMMARY

Surveys and interviews are commonly used data collection tools. Rating scales ask the participant to rate something according to categories. The "answer card technique" is a participant-friendly method to help the participant keep their focus on the survey questions. Open-ended and closed-ended questions are useful for interviewing and certain types of questions are better for some situations. Some data collection situations may occur more often than others may. The data collector should think through these situations early on.

PART VI:
GUIDING PRINCIPLES
FOR DATA COLLECTION

The word 'ohana (family) encompasses the 'oha (offspring) and therefore family encompasses all living things.

OVERVIEW

Each data collection session is unique. Planning helps us become prepared for some of the possible dynamics encountered. Guidelines help make data collection an enjoyable experience.

OBJECTIVES

1. Describe possible dynamics encountered in data collection situations.
2. Identify the data collector's responsibilities in making preparations for data collection, the actual process of collecting data, and ending the data collection session.

POSSIBLE DYNAMICS ENCOUNTERED

There are dynamics that may occur in a research situation because humans are social and interactive. Here are some things to think about before starting to talk story and collect data. Think about how to handle these situations.

Conceptualization of "Family"
Family composition is flexible especially in Hawai'i. Family includes the nuclear family (mom, dad, and children) as well as the extended family (intergenerational) and expanded families (a broader community focus than solely on the child and parents). Family means the community or fellowship. Dual caretaking is a cultural aspect; the parent may be legal guardian while another person provides most of the care. It is recommended that for family studies, the perspectives of many members be included. For example, include the perspectives of the child as well as asking the child's parent, grandparent and teacher for their perspective.

Confidentiality
Talking and sharing is a part of our culture. Sometimes there is conflict between research behavior and one's own personal behavior. In research, all individual data (facts, findings) is confidential; but in one's own personal activities, we may decide to share some things with others who are important to us. Thus research training is essential. Since the research staff has many contacts, others may try to pry for information or attempt to get the research staff to reveal confidential information. People are naturally curious. The research team must be honest with inquiring individuals that the information collected is confidential.

Researchers' Relationship with Team Members
Trust and communication are essential for the research team members. It is recommended for the team to meet on a weekly basis on a set day of the week and time. This will allow each team member to plan their work and report back. Communication with the entire team includes field offices. All team members need to feel included in the project. Formal minutes of meetings are needed.

Researchers' Relationship with the Participants

The role of the researcher will need to be clearly defined to the participant. Some may perceive the researcher as a service provider or a friend. However, the research role is separate from being a service provider or friend. The research role involves objective data collection whereas the service provider role requires the use of a personable approach to convince clients to seek services. The friend role can be partial and may prevent objective consideration. The researcher may form a relationship with the family and may want to continue to foster the relationship; however, it is recommended that the development of any relationship be strictly for the collection of data.

Researchers need to separate their personal behavior and maintain a professional demeanor in order to prevent conflict between research behavior and their own personal behavior. For instance, the researcher may be having a bad day and yet should set aside ones differences and focus on the participant and maintain a professional attitude.

Convey the notion that "Everybody Counts" when talking with participants. Maintain respect for participants at all times – not only when we are seeking their responses (data). When the participant asks a question or makes a suggestion:

1. Recognize the individual's interest in the Project (give credit): "Thank you very much for calling me. It sounds like you're thinking about the Project . . . "
2. Jot down the issue (so you don't forget) and return to it after the data collection: "I'll make a note of it and we'll come back to it when we're done."
3. When the data collection is finished: "You wanted to talk about . . . "
4. Since your role in a research project is not to provide service. Explain that your contact was to collect research information (not service provision) and offer to put the individual in contact with the general intake person, etc. "Since my job was to talk to you about the Project, I'll leave a message with ____ for your other question(s)."

Difficult Emotional Issues for Researchers

Researchers may connect with families and feel anger, sadness and empathy at the experiences the family relates. Sometimes with data collection, the researcher may identify problems that cannot be "fixed." The role of a researcher is not to obtain services for the family or resolve issues, so there is a need to separate researcher role vs. staff role. After the research encounter, the researcher can offer general information about services that are available to the family. During the research encounter, care must be given not to raise families' expectations that something can be done about a problem and then leaving them dangling after the data collection is finished.

Participant Recruitment

Individuals make decisions to participate for many reasons. Some may do so in deference to authority or others may need to talk to someone. In health services or

social service research, some participants may incorrectly perceive that research participation is required to receive services or maintain relationships with health providers. The separation of the provider's and the researcher's roles will help participants make informed decisions about participation in community-oriented participatory research.

Achieving Reliable and Valid Data

Participants have limited time and ability to read surveys. The researcher must figure out if the participants understand the questions. Skill is also needed to prevent socially desirable responses because sometimes participants think the data collector wants a "certain right" answer.

Respect for Participants

The researcher's demeanor and interactions indicate their respect for the participants. Consider the participant's time by offering convenient locations and flexible scheduling. The researcher must be comfortable with the type of participants, for example, culture, life-style, gender.

Safety of Participants

The safety of the participants is a shared responsibility. Researchers need to be able to differentiate abuse and neglect from cultural practices. For emergencies and life threatening situations, the researcher must call 911 followed by calling the project supervisor.

Interpretation of Data

Data interpretation, especially for interviews, may be subjective. The research team imposes their own logic and values onto what the participants say. It is necessary to verify the research team's understanding and interpretations with the participants who provided the data. Share the findings with the participants to make sure the team achieved a representative picture of the participant's stories.

SCENARIO: You complete your interview with Napali, who happens to be a client of your agency. A few days go by and Napali contacts you to find out what happened with the interview results, the people she referred to you for the study, and her glucose readings.

What could you say or do?

Answer: As a community researcher and a health worker, you must clearly separate your two roles. The initial step in the client encounter is to clearly define your roles to your participants and clients. When working in dual roles, make sure you tell the client which role you're representing at this time.

Since you are interviewing the participant for a research project, your role is a community researcher. In this role, you will not be providing services to the participant. Rather, your task is to collect data. Relationship building as a community researcher

should be strictly for data collection. The second role as a health worker is service based. However, in this instance, you are not here to provide services for the participant.

1. Recognize Napali's interest in the Project (give her credit). *"Thank you very much for calling me. It sounds like you're thinking about the Project and your health."*
2. Make a note of Napali's concerns on a scratch notepad so you don't forget: Jot down: *"project results"*, *"referrals"* and *"glucose"*
3. Verify with Napali that you heard her: *"Napali, it sounds like you have questions about three things: the results, the people that you referred, and your blood sugar."*
4. Continue with your explanation (the results are compiled together): *"Let's start with the results. We are talking with many other people right now. When we get to the stopping point, then we will summarize the results. When we make the summary, no one's individual answers will be singled out. Everyone's answers will be pooled together."*
5. Acknowledge Napali's contribution: *"I really appreciate your taking time out the other day to talk with me."*
6. Refocus on the second question (referrals) and acknowledge Napali's suggestions: *"Thank you for making the suggestions about the other people. Tell you what, if you can help me and ask your friends for me, that way, I will not need to know their names yet because it is confidential. After they say 'yes" then can you let me know? I'll follow up."*
7. Address the third point (glucose): ask Napali if she has talked with her case manager about the glucose level. Explain that your contact was to collect research information (not service provision) and offer to put her in contact with her case manager: *"Since my job was to talk to you about the Project, I'll leave a message for Pua. She will have your file."* (Do not say that Pua will return Napali's telephone call – you do not know anything about Napali's relationship with Pua, or Pua's plans. "
8. Thank the participant: *"Napali, it's great to hear from you. I really appreciate your calling today.."*

GETTING READY TO COLLECT DATA

Interviewing and data collection is fun and has a lot of flexibility. These guidelines will help you make data collecting an enjoyable experience.

- The data collector is responsible to collect and record valuable data – that is, the respondent's answers to the questions. There is a strict way (protocol) for recording the data. It must be done the same way with each person.
- Starting with the voice recorder and other project equipment – you are responsible to keep the voice recorder in good working condition. Take care of it; it will break if dropped. Using a voice recorder will help the data collector pay attention to the participant's responses rather than worrying about recording notes.
- After an interview, the tape will contain confidential answers so it cannot be left in the open.
- Time is needed for the data collection – do not forget to think about your travel time and time spent trying to contact the participant.

Hō'ihi or respect is an important part of any culture. Showing respect for the participant through verbal as well as non-verbal behavior can create a sense of trust among participants and project staff.

You have a very important role as a data collector. It is also difficult to maintain your role strictly as a data collector. This means that your contact with the participants is only for collecting the data. This is different from your contact with the clients when you are providing outreach services. Outreach is giving a service to your clients. In data collection, our clients are the teachers and tell us something to help us learn.

Consider the following points:

- Confidentiality is important. Confidentiality means that we cannot tell funny or horror stories about participants, even if names are omitted.
- All persons who take part in the study are "participants" and not "subjects."
- The activity that you are participating in is a "Project" and not "Study."
- Keep all data and project materials in a locked place to maintain confidentiality.
- Contact your supervisor immediately if you think there is actual or suspected child abuse or call 911 for life-threatening situations, and notify your supervisor.
- Your safety is important. If you become concerned about your safety, discontinue the interview. Interrupt the interview without being rude.

Getting Started
First impressions make a difference. All of us have first impressions, whether we are the data collectors or the participants. The following pointers are useful:

- **Structuring the Data Collection Session**
  You are representing the community-oriented participatory research project. Follow your Agency's procedures for using your ID badge. Alternatively, make an ID badge if your Agency or project team doesn't have one. Also, have some project business cards available. These cards can be given to the participants for future reference or in case they have someone else to refer to our study.

- **How to Dress**
  Participants will consider your appearance. Make sure your clothing is neat and clean so the participants are comfortable with your appearance. Your clothing should fit the participants' expectations of your appearance.

- **Initial Interaction with the Participant**
  The initial interaction of the data collector with a participant usually determines if cooperation will follow. Not all participants will be easy to approach. Everyone may encounter reluctant or suspicious participants and this does not mean you are at fault.

  - Give an open-minded and non-judgmental impression
  - Have a positive attitude
  - Be optimistic about your ability to persuade respondents to participate.
  - Be respectful as each participant is a volunteer who is offering to assist in the Project

- **Telephone versus Personal Contact**

  Sometimes it is easier to refuse on the telephone than in a face-to-face situation. Thus, in the first contact, approach a potential participant in person, and in later follow-up, don't use the telephone if the participant seems reluctant.

- **Answering Machines or Leaving Messages**

  If you need to leave a message with a person or on an answering machine, state your name, affiliation, phone number and ask for the person to return your call. Do not provide details about the purpose of your call. Speak slowly and clearly.

- **Giving Information about the Study**

  Sometimes participants may ask you to describe the study. Make sure you know enough about the background of the study to explain. Be ready to answer questions such as:

  - ◆ Why the participant was selected.
  - ◆ Why the Project (study) is being done.
  - ◆ How the information will be used.
  - ◆ Keep in mind that participants are only interested in a general explanation. If you cannot answer a question, tell the respondent that you do not have this information but that your supervisor will get in touch with the participant as soon as possible.

- **Telling Participants about the Length of the Data Collection Session**

  Discuss with the participant the approximate length of the session. Negotiate a follow-up session if the participant does not have enough time. Participants do not want to have their time taken for granted. Do not tell a participant that the length of the interview will depend on the answers that they give (they may start to answer "no" in order to not have to deal with the follow-up questions).

- **Explaining the Data Collection Session**

  Make sure to let the participant know that they are the expert on what the interviewer wants to know. Let the participants know that accurate and complete answers are important. The participant is the expert and we want to learn from them.

  Sometimes participants may challenge the data collector on specific questions or parts of the interview. Instead of discussing the alternative ways of data collection, explain the necessity of maintaining a standardized way for gathering the information. All participants will be asked to answer the same questions, and reassure the participant that their comments will be passed on to the research team.

Kūpono or honesty and fairness can enable all participants to feel a sense of belonging in the Project.

- **Data Collection Environment**
  The participants' home is not always the best place to conduct an interview.

  - In large households, a private place to conduct the interview may be hard to find.
  - The participant's home may be considered a private place.
  - The participant may feel obligated to clean up their house and "entertain" the data collector as a guest.
  - Sometimes children and others compete for attention during the interview.
  - Participants may not like to have strangers or guests in their homes – they may be embarrassed about their living conditions.
  - Living and dining rooms are the most common places for in-home interviews. Try to sit as closely as possible to the participant with out invading their privacy so you can conduct the interview in a low voice (keeps others from overhearing the questions).
  - Ask the participant to have their back turned towards the TV or ask if the TV can be lowered in volume (too distracting).
  - When children are expected to be a distraction, bring coloring books and toys for the child's entertainment. Alternatively, bring a second person to entertain the child(ren).

If there is little chance for privacy inside the house, other possible places to conduct the interview are outside on the lanai, under a tree, in a car, or at some nearby public place. Negotiate this prior to starting the data collection with the participant. If the interruptions start to happen after the data collection has begun, temporarily stop the session and discuss privacy issues.

- **Maintaining a Professional Relationship**
  The most effective way to complete each interview is to combine a friendly attitude with a business sense of purpose. DO NOT express your comments or opinions in response to participants' answers.

  - Try not to accept offers of food or beverage – this will make the interviewing time longer and make the participant feel they need to entertain the data collector
  - If the participant has prepared some food in advance and then it would be rude to not eat a little of it
  - No smoking or alcoholic beverages

- **Ending the Data Collection Session**
  Leave the participant with a positive feeling about the project. Since the participant has just given a lot of information that may be personal and sensitive in nature, give the participant an opportunity to reflect on the interview and ask if they have any questions or comments. Make sure you communicate any comments to the research team (or the data collector can record their comments at the end of the participant's tape).

SCENARIO #1: You call to reconfirm an appointment with a participant; a member of the household answers the phone and asks why you are calling. The household member is persistent and continues to ask you why you are calling.

How would you handle this situation?

Answer: Politely, in an even tone, with a controlled voice reply that you will call back. Thank the individual.

SCENARIO #2: It is your first time going to a specific location to collect data. You are not sure about where to go, or how the environment of the neighborhood will be like.

How would you handle this situation?

Answer: Your safety is of importance. There are several considerations:

1. Ask the participant to meet with you in a public place (nearby park, Zippy's, McDonalds, etc).
2. Ask a co-worker to go with you.
3. Schedule the data collection visit during daylight hours.
4. Call the participant with your cell phone as you are arriving and ask them to meet you at your car and accompany you into their home/data collection location. Make sure that your valuables are not visible inside your parked car.
5. Devise a "call in" system where the data collector calls in to an appointed person after returning from the data collection session.

SCENARIO #3: As you enter the participant's home, they bring out soda and cookies. Aunty A. insists that you "have a taste of her cookies, and take plenty."

What would you do?

Answer:

1. Politely, thank Aunty A and recognize her efforts. *"Wow Aunty, you made this so nice."*
2. Take a small sample (if possible) and nibble on it just a little bit at the start of the data collection activities.
3. At the end of the data collection session, tell Aunty that you didn't finish, and you'll take the cookie with you: *"You know Aunty, I got so into talking with you that I forgot to finish (e.g., blame yourself). How about I'll take it with me? It was so ono- da best (really tasty)."*
4. Thank Aunty for her efforts.

SUMMARY

Humans are social and interactive. Commonly encountered dynamics which may influence the data collection session are: the flexible family composition in Hawai'i, maintaining confidentiality, keeping relationships with team members and with the participants, dealing with difficult emotional issues, recruitment, achieving reliable and valid data, respect and safety for participants and the interpretation of the data. The role of the data collector is only for gathering the data. This is different from providing services or outreach to clients. Each data collector represents the project to the community. The responsibilities of the data collector include helping the participants feel a sense of contribution to the project.

OVERVIEW

This is the final section of the Participatory Research Manual. In this section, we will provide some reasons for why individuals ask questions. Commonly asked questions are listed along with a sample answer for each question.

OBJECTIVES

1. Identify the reasons that individuals may ask questions.
2. State answers to commonly asked questions about a community-oriented research project.

ANTICIPATE QUESTIONS

Anticipating questions will help us think through the answers. This will help our answers be clear and thoughtful.

- What experiences have the participants and research team members had with this Project and other similar studies?
- What are the expectations of the Project?

Questions are asked for several different reasons:

- Individuals may want to find out about the Project. They are interested and are seeking more information. Response strategy: Provide a short and clear response. Don't forget to ask the person for their thoughts and ideas too!
- Individuals ask questions but are really making a statement. Don't try to answer the statement. Response strategy: Thank the person for the comment and continue with whatever you were talking about.
- Questions may be asked to offer assistance or get attention. Response strategy: Provide a short and clear response.
- Questions may be asked to show a problem with the Project. Response strategy: Provide a short and clear response; repeat the reason for the Project and why the project is important. Briefly describe the procedures.

COMMONLY ASKED QUESTIONS

Can I see a copy of the final report?
Sample answer: Sharing results is important for Projects that are conducted in the public and nonprofit setting. Sharing results means the project is open and allows us to develop positive attitudes for all sides to work together.

Is this community research scientific?
Sample answer: There are many different types of scientific research. The community approach is social science research. In comparison to research that takes place in labs, this type of a project makes adaptations to fit everyday human experiences. Yes, community research is scientific because it follows a process that is systematic and can be verified. The goal of this type of research is to describe and to provide understanding.

How can you tell that this is an accurate reflection of the results?
Sample answer: The research team has taken several steps to make sure the results accurately reflect what the participants told us. The questions were field tested to make sure they were understandable. We had an advisory panel (families, researchers, clinicians and community members) help design the Project. We also followed an accepted protocol to analyze the data.

Can we generalize (apply) the results to other communities?
Sample answer: This study is intended to describe what is happening in detail, so it is not intended to generalize (apply the findings to other situations). If someone else wants to use the results, they should consider if the results can be transferred into their setting or situation. In other words, they should consider if our methods, procedures and type of participants will fit their situation.

What becomes of the findings?
Sample answer: The results are shared with the participants. There are many ways to use the findings:

Community self-development:

- Provide information for community self-development
- Provide information for community education by other community-based health care organizations
- Provide a voice for those who participated to tell about their experiences and what is preferred
- Develop information to be disseminated at community functions such as health fairs

Foster communication:

- Provide information to health care providers
- Facilitate access to care for agencies and service organizations by providing information on what helps and what doesn't help

Plan Health Programming:

- Provide data to plan health programming in the community
- Share findings with community leaders as to what the participants found helpful
- Plan and develop community-based interventions

Who will use the data?
Sample answer: Although there are no direct benefits to the participant, the intent of this community oriented participatory research study is to provide information for community self-development and evidence for designing community-based interventions to reduce and eliminate barriers to health care.

The results will be used to improve the community's health conditions. Community coalition planning involving community residents, key community members and health care practitioners will allow for planning appropriate interventions. We are collecting the data to help us understand some of the barriers towards health care and how to keep the community healthy. This information is needed so we can make improvements.

There may be separate members of the team who wish to use specific portions of the data as well. For example, the schools may want to make a bulletin board display, an agency may want to make a brochure or the agency and research staff may wish to write an article in the newspaper.

Will people see my individual answers?
Sample Answer: Individual answers are not revealed. Only synthesized, grouped data that is without individual names, are released.

Why can't I see my child's answers?
Sample Answer: All participants' answers are held in confidence (confidentiality). If your child wants to discuss their answers with you it's okay, but do not push the child to share.

I think you should talk with my cousin; she has two children with diabetes.
Sample Answer: We would love to include your cousin in our project. Here is a flyer for your cousin. It has our project contact information. Ask her to contact us directly. (Confidentiality of client information prevents us from contacting the individual directly.)

How is my data stored?
Sample Answer: All data is stored in a locked file cabinet at the project office. The consent form and contact information is placed separately from the data (i.e. interview transcripts, survey). In addition, any data placed in a computer database is password protected. Only the research team has access to the data. Your name and ID number will not be linked with the data.

SUMMARY

Anticipating questions will help us become prepared. Individuals ask questions for different reasons, such as wanting more information, to make a statement, or to show a problem. Sample questions and responses are provided.

EXAMPLE

We offered a summary of the Project's results to each participant. They provided their contact information on a "Request for Project Results" Form. This Form was kept separate from the data because it contained names and addresses.

The unprocessed data (i.e., each individual's surveys or interview results) are not shared because of our promise of confidentiality.

REFERENCES

Discussions with the "Family Perspectives of Asthma Project" Key Team:

    Alice Tse, PhD, APRN
    Donna-Marie Palakiko, RN, MS
    Jolene Lono, MSW
    Haliaka Rodrigues, CNA, Outreach Staff

Harrison, B. (2001). Collaborative programs in indigenous communities: From Fieldwork to Practice. Walnut Creek, CA: Altamira Press.

Holkup, P.A., Tripp-Reimer, T., Salois, E.M. and Weinert, C. (2004). Community-based participatory research: An approach to intervention research with a Native American community. Advances in Nursing Research, 27, 162-175.

Minkler, M and Wallerstein, N. (2003). Introduction to community-based participatory research. In: Minkler, M. and Wallerstein, N. (eds). Community-based participatory research for health. San Francisco: Josey-Bass.

Native Hawaiian Health Care System (NHHCS) IRB Report. (2004). Papa Ola Lokahi/'Imi Hale, Honolulu, HI.

The Belmont Report (1979). Ethical principles and guidelines for the protection of human subjects of research. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Washington, DC: Department of Health, Education, and Welfare.

The Nuremberg Code [from Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10. Nuremberg, October 1946–April 1949. Washington, D.C.: U.S. G.P.O, 1949–1953.]

Tse, A.M. (2002). Family perspectives of asthma project. A Joint Community-Oriented Research Project by Department of Pediatrics, University of Hawai'i, Ke Ola Mamo, and Hui Mālama Ola Nā 'Ōiwi. Funded by Supported by the U.S. Department of Defense Pacific Telehealth and Technology Hui, Contract #1435-04-03-CT-87084.

U.S. Department of Health and Human Services. (1998). Call to action: Eliminating racial and ethnic disparities in heath. Washington, DC: Author/Grantmakers in Health.

U.S. Department of Health and Human Services. (2000). Healthy people 2010. Understanding and improving health. Washington, DC: Government Printing Office.

U.S. Department of Health and Human Services. (2004). HIPAA Privacy Rule. National Institutes of Health, Washington DC: http://privacyruleandresearch.nih.gov/ site updated 8/4/2004.

Researchable issues come from a variety of sources. In community-oriented participatory research, "community" is dynamic and inclusive; there is no "single" definition of community. The key question should be: "Are the individuals most affected by the issue being addressed at the table?"

SAMPLE FORMS

In the Appendix, we provide examples of some of the Forms used in the Family Perspectives of Asthma Project (Tse, 2002) and give examples of how-to strategies. The contents of the Appendix are provided to give ideas for furthering community-oriented participatory research activities. Please feel free to modify our forms for your project's use.

Family Perspectives of Asthma Project

A Community-Oriented Research Partnership

INTERVIEW/DATA PREPARATION CHECKLIST

Consent
- ☐ Consent
- ☐ Assent
- ☐ Asthma Reporting Form

Interview
- ☐ Recorder
- ☐ Tapes with blank ID stickers
- ☐ Batteries
- ☐ Zip lock bag with ID number tag

Survey and Interview Forms
- ☐ Interview Forms
  - Child
  - Sibling
  - Parent/caregiver
  - Community Member
  - Practitioner
- ☐ Child Health
  - Child 11 years or older or Child 6-10 years
  - Sibling 11 years or older or Sibling 6-10 years
- ☐ Children's Perception of Asthma
  - Child Version
  - Sibling Version
- ☐ Demographic Forms
  - Family
  - Community Members /Practitioners
- ☐ Family Hardiness Index
- ☐ Paediatric Asthma Caregiver's Quality of Life Questionnaire
- ☐ Paediatric Asthma Quality of Life Questionnaire
- ☐ Parent Report of Family Health

- ☐ Response cards

- ☐ Pass Card

General
- ☐ Data Collection Summary Form
- ☐ ID number [Family ID, role]
- ☐ Flyers (Ke Ola Mamo, Asthma Information)
- ☐ Business Card
- ☐ Makanas (gifts)
- ☐ Legal Pad
- ☐ Sign out data collection kit
- ☐ Sign in Kit

PROJECT TRACKING FORM

Participant Contact Record	
Client Name:	Date:
Last First M.I.	
Street Address:	City:	Zip Code:
Home Phone #:	Work/Other Phone #:
Best Time to Call:	OK to leave a message? yes☐ no☐

| How did you find out about this project? | ☐ Flyer   ☐ Physician | ☐ Friend   ☐ Clinic | ☐ Web   ☐ Other: _____ | ☐ Health Fair |

Project Assignment

DISTRICT: ☐ Ko'olauloa   ☐ Ko'olaupoko   ☐ Urban-Honolulu   ☐ Wai'anae

Consent By: _____ Date Consented: _____
Assigned to: _____ Date Staff Notified: _____
ID NO: _____ Data Collection Date/Time: _____
Kit Prepped By /Date: _____ Kit Checked In By/Date: _____

PARTICIPANTS:

☐ Parent/Caregiver	☐ Child	☐ Sibling	☐ Practitioner	☐ Community Member
☐ Interview	☐ Interview	☐ Interview	☐ Interview	☐ Interview
☐ Surveys	☐ Surveys	☐ Surveys		

DATA COLLECTOR SIGN OUT   Kit No. _____   Signature: _____   Date/Time: _____

FORMS RECEIVED	Caregiver	Child	Sibling	Community	Practitioner	Interviewer
Consent or Assent						
Interview (all completed tapes must be labeled)						
Asthma Reporting Form						
Child Health						
Child Perception of Asthma						
Demographics						
Family Hardiness Form						
Pediatric Asthma Caregiver QOL Questionnaire						
Pediatric Asthma QOL Questionnaire						
Parent Report of Family Health						
Data Collection Summary Form						

	Sibling	Child	
MAKANA PROVIDED: ☐ Parent/Caregiver	☐ 6-7 year old ☐ 8-12 year old ☐ 13-14 year old ☐ 14+ year old	☐ 6-7 year old ☐ 8-12 year old ☐ 13-14 year old	☐ Community Member ☐ Practitioner

DATA COLLECTOR SIGN IN   Signature: _____   Date/Time: _____

INTERVIEW GUIDE - CAREGIVER/PARENT VERSION
(page 1 only)

Introduction: Hi _____, my name is _____. Thank you for agreeing to talk with me today. I am going to be talking with lots of parents/caregivers like you, who have responsibility to take care of a child with asthma. I want to talk with you because I think there's a lot you can teach us and help us understand. Your answers will help us learn how to do a better job with taking care of Native Hawaiian children who have asthma.

I want to pay full attention to what you tell me, so is it OK if I use a tape recorder? The tape recorder will help me take notes so I won't have to write down so much.

[TURN ON TAPE RECORDER]
Thank you, so it is OK with you to use this? All of our tapes will be erased right after we get the information off the tapes.

Ready to begin?

Everyone gets sick once in a while, like colds, or flu, and cuts, or chicken pox. Sometimes people have conditions that they live with everyday, like [child's name], having asthma. I'm going to ask you some questions about how you feel about [child's name's] asthma and how you think others feel about it. There are no wrong answers…this is not a test. I think anything you have to share with me will be helpful. If any of my questions make you feel uncomfortable or embarrassed, then tell me you want to "Pass and go to the next question". Also, if you want to change your answer on any of the questions you already answered, I am happy to do that too. All your answers will be between you and me. I will not tell anyone what you told me. You are one of 30-40 parents/caregivers that I will be asking the same questions. When I'm finished, I will put all the answers together but will never tell anyone which answers were yours.

Any questions?

Remember that if you don't want to answer any of the questions, tell me and I will skip that one. OK?

Let's start by talking about what is asthma.

[WHAT IS ASTHMA?]
>   What do you think of when you hear the word "asthma"?
>   What do the other people in your family/caregivers call it?
>   Do you feel comfortable saying "asthma" or do you want to use other words? **(IF OTHER WORDS, ASK WHAT THE WORDS ARE AND THEN FOR THE REST OF THE INTERVIEW, USE WHATEVER WORDS THE PARENT/CAREGIVER HAS DECIDED TO CALL "ASTHMA")**

[PERSPECTIVE OF ASTHMA]
Some families prefer that their doctor comes right out and tells them that their child has [asthma]. Other families don't want to know the specific diagnosis.
>   What about you?
>   What did the doctor call it before they told you for sure?
>   Has [child's name]'s doctor told you specifically that [he/she] has [asthma]?
>   Did you want to know that? Why is that so?
>   Or, is it better not to be specifically told? Why?

SAMPLE SURVEY

Parent / Caregiver Report of Family Health

Circle the number to show your answer:

How is your health?				
1 Very Good	2 Good	3 So-So	4 Bad	5 Very Bad

How is the child's health?				
1 Very Good	2 Good	3 So-So	4 Bad	5 Very Bad

How is the child's asthma?				
1 Very Good	2 Good	3 So-So	4 Bad	5 Very Bad

How is the sibling's health?				
1 Very Good	2 Good	3 So-So	4 Bad	5 Very Bad

SURVEY RESPONSE CARD

1. Very Good

2. Good

3. So-So

4. Bad

5. Very Bad

The Family Perspectives of Asthma Project

Ke Ola Mamo & Department of Pediatrics, University of Hawai'i

The Family Perspectives of Asthma Project wants to share the results with you. Please fill out this form if you are interested in receiving the results. It will take some time before the results of our Project will be ready. We'll be happy to send you a copy of the results as soon as we can.

There are three easy ways to return this form to us:
1. By mail: Simply fold this Form in half, place a stamp and mail to:
   Ke Ola Mamo, Native Hawaiian Health Care System, 1505 Dillingham Blvd., Room 205, Honolulu, Hawaii 96817
2. Fax the form to 848-8001
3. Telephone us: 848-8000

Request for Project Results

Your Name:		Date:
Last First M.I.		

Street Address:	City:	Zip Code:
Mailing Address:	City:	Zip Code:

If mailing, fold this form in half and tape it closed.
The address is on the backside. MAHALO

BACK SIDE OF THE REQUEST FOR PROJECT RESULTS FORM

(fold here and secure with tape before mailing)

> First Class
> Postage
> Stamp is
> needed

Ke Ola Mamo
Native Hawaiian Health Care System
1505 Dillingham Blvd., Room 205
Honolulu, Hawaii 96817

Attention: Donna Palakiko, RN, MS

SERVICE REQUEST FORM

Ke Ola Mamo
Native Hawaiian Health Care System, Oahu

Ke Ola Mamo wants to hear from you. Please fill out this form if you are interested in learning more about Ke Ola Mamo's services.

There are three easy ways to return this form to us:
1. By mail: Simply fold this Form in half, place a stamp and mail to: Ke Ola Mamo, Native Hawaiian Health Care System, 1505 Dillingham Blvd., Room 205, Honolulu, Hawaii 96817
2. Fax the form to 848-8001
3. Telephone us: 848-8000

Request for Service Form			
Your Name:			**Date:**
Last First M.I.			
Street Address:	City:	Zip Code:	
Mailing Address:	City:	Zip Code:	
Home Phone #:	Work/Other Phone #:		
Best Time to Call:	OK to leave a message? yes ☐ no ☐		

How Can We Help?

- ☐ Ho'oikaika (Fitness & Nutrition Program)
- ☐ Dental Program
- ☐ Lei Ānuenue (Health Education & HIV Testing)
- ☐ BCCCP (Breast & Cervical Cancer Control Program)
- ☐ Med Quest (Health insurance)
- ☐ Health & Human Services / Financial Assistance
- ☐ OTHER: (please be specific)

If mailing, fold this form in half and tape it closed.
The address is on the backside. MAHALO

FOR INTERNAL USE - Date Received:		Received By:		
Route to	Assessment	Action	Referred To	Date

BACK SIDE OF THE REQUEST FOR SERVICE REQUEST FORM

(fold here and secure with tape before mailing)

First Class
Postage
Stamp is
needed

Ke Ola Mamo
Native Hawaiian Health Care System
1505 Dillingham Blvd., Room 205
Honolulu, Hawaii 96817

Attention: Donna Palakiko, RN, MS

<div style="border: 1px solid">

Closure Checklist

After the interviews and surveys are finished

- ☐ Explain that a nurse will call about the Asthma Reporting Form

- ☐ Verify contact information on the Participant Contact Record

- ☐ Give Request for Project Results Form
- ☐ Give Request for Service Form
- ☐ Give Yellow project flyer (Know Children with Asthma)
- ☐ Give business card

- ☐ Give Makana to parent/caregiver
- ☐ Give Makana to child (and sibling) –
  may also give after the child/sibling immediately after their data collection

Upon returning to the Office

- ☐ Fill out the Data Collection Summary Form – put with the family's data

- ☐ Label all tapes with participant's indicator – write on the sticker
  (DO NOT WRITE ON CASSETTE):
  - PC = Parent/caregiver
  - C = Child
  - S = Sibling
- ☐ Place all completed tapes into the Ziplock bag
- ☐ Make sure the green family ID tag is in the Ziplock bag
- ☐ Check that all forms are labeled with the Family ID number

- ☐ Return the kit to the Site Coordinator

</div>

UNIVERSITY OF HAWAI'I AT MĀNOA

John A. Burns School of Medicine
Department of Pediatrics

Consent to Participate in a Research Study
Parent/Caregiver

TITLE OF STUDY: Perceptions of Barriers and Facilitators to Pediatric Asthma Management in Native Hawaiian Children

PRINCIPAL INVESTIGATOR: Alice Tse, PhD, APRN
Associate Professor of Pediatrics and Nursing
Department of Pediatrics
John A. Burns School of Medicine
Kapiolani Medical Center
1319 Punahou Street, Honolulu, HI 96826
(808) 983-8387; pager 252-0147

NAMES OF CO-INVESTIGATORS:
Donna-Marie Palakiko, RN, MS (Ke Ola Mamo)
Kara Yamamoto, MD
Joelene Lono, BSW (Ke Ola Mamo)
Louise Iwaishi, MD
Malia Young, RN

INTRODUCTION:
Before you decide whether or not to participate in this study, you must understand the purpose, how it may help you, any risks to you, and your rights as a research participant. This process is called informed consent. The consent form gives you information about the study and it will be discussed with you. Once you understand the study, and if you agree to take part, you will be asked to sign this consent form. A copy will be given to you to keep for your reference.

Before you learn about the study, it is important that you know the following:
- Taking part in this study is of your own free will.
- You may decide not to take part in the study or stop being in the study at any time. If you decide that you don't want to be part of this study, there will be no penalty to you and you will still receive any benefits that you are normally entitled to.

It is important that the following explanation of the proposed procedures be read. It describes the purpose, procedures, benefits, risks, discomforts and precautions of the study. It also describes alternative procedures available and the right to withdraw from the study at any time. No guarantee or assurance can be made as to the results. Refusal to participate in this study will not penalize you in any way.

Kapi'olani Medical Center for Women and Children, 1319 Punahou Street, Honolulu, Hawaii 96829
Telephone: (808) 983-8387; Facsimile: (808) 945-1570

An Equal Opportunity/Affirmative Action Institution

We will be inviting many different people to participate: parents/caregivers of children, children, their brother/sister, traditional and western practitioners, and community members. You will be one of approximately 450 people (parents/caregivers, children with asthma, the child's brother/sister, practitioners and community members) to take part in this survey.

About 120 parents/caregivers and their children from several age groups and the child's brother/sister will participate in an interview and about 400 parents and children will complete some surveys. If you and/or your child are one of the first 8-10 individuals of each age group, then you will be invited to talk story with us and also answer the surveys. If you and/or your child are not one of the first 8-10 individuals of each age group, then you will be invited to answer the surveys.

PURPOSE
We want to learn more about what doesn't work and what helps in taking care of Native Hawaiian children who have asthma. We also want to learn how having asthma impacts the family. We are asking permission to talk with you as a parent or the child's caregiver, the child (age 6-14 years old) who has asthma, and if your child has siblings, we would be interested in talking story with the brother or sister who is closest in age to your child.

LENGTH OF TIME NEEDED:
The first 120 parents/caregivers or children will be invited to talk story interview and fill out some surveys. The interview for the adults should take about 30-45 minutes, and the interview for the child will take about 20-30 minutes. For the people who participate in the interview, we will also invite you to fill out some surveys after the interview. If you are not one of the first 120 persons, we will invite you to fill out the surveys. The surveys should take about 20 minutes. If you are participating in both the interviews and the surveys, you will only be asked to talk with the data collector at one time or if you prefer, the data collector can split the process into two separate times.

PROCEDURES:
If you decide to allow us to talk story with you and your child, the data collector, who is a member of the Native Hawaiian Health Care System Outreach Staff, will help with the interview and giving you the forms to fill out.

In appreciation of your time and effort, a small gift or compensation worth about $10 will be given to each parent/caregiver who participates in the study. We will not give any money, but will give each child who participates some school supplies or a gift certificate for adults. You do not need to finish the whole study in order to receive the recognition.

You will be talking with either the RN Project Coordinator or a trained data collector. The data collectors are trained outreach staff. We will make an attempt to assign a data collector who does not provide service where you live; rather we will try to assign another worker from another neighborhood to collect data where you live. We are doing this because we want to keep the research and service activities separate.

The data collector will talk with you by yourself or your child or the child's brother/sister by themselves. We want your ideas. There are no correct answers. If you change your mind, you can stop talking at any time. If you or your child/sibling decides to stop talking with us, it will not affect your relationships with the Native Hawaii Health Care System, any practitioners or service agencies.

If you are giving us permission to talk with your child, please do not ask your child or their sibling to tell you what they said to us.

FORESEEABLE RISKS OR DISCOMFORTS:
There are no risks or discomfort that we foresee in completing this study. Some of the questions may make you feel embarrassed, but you can skip over those questions. Maybe you may begin to start thinking about your child with asthma in your family, or you may get tired of talking or bored with the data collector. If you do experience any discomfort or other problems while completing this study please inform the data collector right away.

BENEFITS:
You will receive no direct benefit from participation in this study, but your participation may help the community, practitioners and health care workers better understand what we can do to help Native Hawaiian children manage their asthma better. The results gained from the study will help develop and validate community based initiatives and will be used to develop community-based programming by the community. Although there are no direct benefits to the participant, the results of this study is to provide information for community self-development and for designing community-based interventions to improve the respiratory health of children in Hawaii. It will also identify factors that influence how children and their families take care of pediatric asthma. The results will be used to improve the community's methods of asthma management by sharing our findings on how to improve asthma intervention protocols

CONFIDENTIALITY:
Your name or your child's/sibling's name will not be used in reporting the results of this study. Every effort will be made to maintain the confidentiality of your study records. All information about you will remain strictly confidential to the extent allowable by the law. Results from this study may be published or shared with other interested groups such as other physicians, research institutions and/or federal authorities, but you or your child will not be personally identified. In the process of evaluating the study, your records may be examined by Agents of the United States Food and Drug Administration (FDA), the University of Hawaii Committee on Human Subjects, or the Native Hawaiian Health Care Systems IRB. Your identity will remain confidential unless disclosure is required by law.

FINANCIAL COSTS TO THE SUBJECT:
There are no financial costs to the participants.

VOLUNTARY PARTICIPATION STATEMENT:
I understand that my participation in this study is completely voluntary and that I may either refuse to participate or withdraw from the study at any time without penalty or loss of benefits to which I am otherwise entitled. I have also been told that the investigator has the right to withdraw you from the study AT ANY TIME. I have been told that my withdrawal from the study may be for reasons related solely me (e.g. not following study-related directions) or because the entire study has been terminated. I have been told that the sponsor has the right to terminate the study or the investigator's participation in the study at any time.

IF YOU HAVE QUESTIONS.
I understand that any questions I have about the research study and/or specific procedures should be directed to Alice Tse, Department of Pediatrics, 1319 Punahou Street, Honolulu, HI 96826, phone # 983-8387 or 252-0147. In the event of injury I should contact Alice Tse, pager 252-0147. Any other questions that I have regarding your rights as a research participant or if you cannot obtain satisfactory answers to your questions or have comments or complaints about your treatment in this study, should be directed to (1) the Chair of the Native Hawaiian Health Care Systems Institutional Review Board (phone: 808-597-6550) and (2) the Chair of the Committee on Human Studies, University of Hawaii, 2540 Maile Way, Honolulu, Hawaii 96822. (phone: 808-956-5007).

UNDERSTANDING AND COMPLIANCE.
My signature below indicates that I have read and that I understand the procedures described above and give my informed and voluntary consent to participate in this study.

VOLUNTARY CONSENT:
I certify that I have read and that I understand the above information, and that I have been given satis-factory answers to my questions about project procedures and other matters and that I have been advised that I am free to withdraw my consent and to stop participation in the project at any time with-out prejudice and will not affect the other care that I receive.

I give my consent to participate and consent to the participation of my minor child(ren) OR minor ward in this project with the understanding that such consent does not waive any of my legal rights, nor does it release the principal Investigator or the institution or any employee or agent thereof from liability or negligence.

A COPY OF THIS CONSENT FORM WILL BE GIVEN TO ME.

_____   _____
Printed Name of Participant   *Date*

_____
Signature of Participant

_____
Printed Name of Minor
if the minor's last name is not the same as the parent/caregiver

_____   _____
Signature of Investigator   Date

If you have any questions about your rights as a research subject, you may call the Chairman of the Native Hawaiian Health Care Systems Institutional Review Board at 808-597-6550 or send written correspondence to 894 Queen Street, Honolulu, Hawaii 96813 as well as the Chairman of the Committee on Human Studies, University of Hawaii, 2540 Maile Way, Honolulu, Hawaii 96822.
(phone: 808-956-5007).

UNIVERSITY OF HAWAI'I AT MĀNOA

John A. Burns School of Medicine
Department of Pediatrics

Assent Form
Children under 18 years old

Title of Study:
Perceptions of Barriers and Facilitators to Pediatric Asthma Management in Native Hawaiian Children

Principal Investigator: Alice Tse, PhD, APRN,
Associate Professor of Pediatrics & Nursing
Department of Pediatrics
John A. Burns School of Medicine
Kapiolani Medical Center
1319 Punahou Street , Honolulu, HI 96826
(808) 983-8387

Names of Research Team: Donna-Marie Palakiko, RN, MS
Kara Yamamoto, MD
Joelene Lono, BSW
Louise Iwaishi, MD
Malia Young, RN

We would like you to help us in a research study. Before you decide to help, you need to read this form and ask any questions you have. We want to make sure you understand what you will be asked to do.

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Study Purpose: Why are we doing this?

The purpose of this study is to help us learn about what doesn't work and what helps for taking care of Native Hawaiian children who have asthma. We also want to learn how it is like for your family. We are asking permission to talk with you.

Study Procedures: This is what will happen in the study

With your parent's permission, an adult will talk with you by yourself about asthma and your ideas of what helps and doesn't help you with taking care of your asthma. We want your ideas. There are no right answers. We will not tell your parent what you said. They will only know that you talked with us. You will be one of about 320 kids we will be working with. You will be asked to answer some surveys which look like pages from your workbook from school. It will take about 30 minutes which is about how long a TV program lasts. If you are one of the first 8-10 children of each age group, then we will ask you to talk story with us for about 30 minutes too.

Risks and Discomforts:

Some of the questions may make you feel embarrassed, but you can skip over those questions. You may start to think more about your asthma, or you may feel bored by the questions.

Benefits:

Your answers on this survey may help us figure out what makes it easier for you and your family to take care of your asthma. We want to find out what really works for kids like you.

Confidentially:

We will not use your name or your parent's/caregiver's name when we report what we find in this study.

It's Your Choice:

*You don't have to be in this study if you don't want to. **Also, you can decide to be in the study now but change your mind later, and stop. No one will be mad at you and your doctors will still take care of you.***

Recognition for Kids Who Participate:

Because you will give us your time and effort, school supplies that are worth about $5 will be given to each kid who is asked to participate. You do not have to finish the surveys or talking story part in order to get the school supply or gift certificate.

Questions:

If you have any questions while you are in the study, call **Alice Tse** at any time. The phone number is **983-8387**.

If you have questions about your rights as a research participant, you may contact the Native Hawaiian Health Care Systems Institutional Review Board, call 597-6550, or write to 894 Queen Street Honolulu, Hawaii 96813. You may also contact the Committee on Human Studies, University of Hawaii, 2540 Maile Way, Honolulu, Hawaii 96822. Phone: (808) 956-5007.

Signatures:

If you have any questions about the study, you can ask the study doctor or the nurse. They will tell you anything about the study you want to know.

I have been told about the study and what I will need to do if I agree to be in it. I know that I can choose to say either yes or no. I also know that if I start the study, I can stop at any time if I change my mind. If I have any questions, I can ask the adult who will be talking with me.

Check one of the statements below:

____ *I want to be in the research study.*

____ *I **do not** want to be in the study.*

_____

Write your name here (print)

_____   _____

Sign your name on this line   **Write the date here**

I have fully explained the research procedures and their purposes. I have asked whether there are any questions, and have answered all questions to the best of my ability.

I believe that _____ (name of child) understands all of the essential information.

_____
Date

_____   _____

Responsible Investigator/Coordinator   Printed Name
Signature

amily Perspectives of Asthma Project
A Community-Oriented Research Partnership

What's Up This Week?
Date: August 11, 2004

Contact Donna-Marie Palakiko <dpalakiko@keolamamo.org> or Alice Tse <atse@hawaii.edu>

Hmmm, Better to PUFF than HUFF

Inhalers- What are they?
Inhalers provide pre-measured amounts of medications directly to the lungs through the process of inhaling. Inhaling means "breathing in"- thus the name "Inhaler". Inhalers are compact hand-held devices that are easily carried in your pocket, hand bag or backpack. Inhalers can provide relief to an individual experiencing an asthma episode (short-acting) or control asthma symptoms (long-acting). Inhalers can be used as needed to treat an asthma episode or daily to control/prevent an asthma episode.

> HUFF
> HUFF HUFF
> PUFF PUFF
> PUFF
> **PHEW!**
> I feel better already
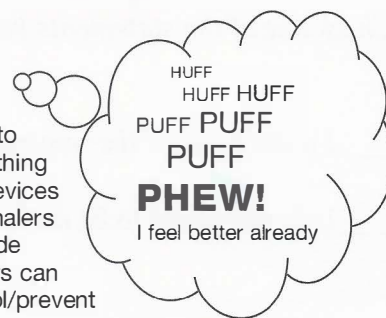
IMPORTANT TIP: carrying an inhaler in your pocket, handbag or backpack does not help take care of asthma symptoms **UNLESS** the inhaler is properly used! Check with the doctor to ask for clear directions. As keiki grows, the directions and dosage may change.

Inhalers come in many shapes and forms but the most common types are:
1. **Meter Dose Inhalers (MDI's)** – The medication is delivered by inhaling a fine spray into the lungs. The medication is administered through squeezing the canister or through direct inhalation. The person using this type of medication needs to keep track of the number of doses received from the inhaler.
2. **Dry Powder Inhalers (DPI's)** – The medication is delivered through forceful inhalation of tiny grains of powder. The number of dosages remaining is indicated on the inhaler.
3. **Nebulizer** – Medication is delivered through inhalation of mist. This delivery method is not compact and is generally used on infants, young children and seriously ill individuals.

But I'm not HUFFING. Why do I need to use an inhaler?
Prevention is much better than having an asthma attack! There is no shame in using an inhaler. Many keiki just turn and face away from their friends and use their "puffer" (inhaler). If the friends see that using the inhaler helps keiki keep up in sports, play or bumming around, they will accept it as a normal thing. Inhalers are only one part of controlling your asthma. Remember that being aware of triggers help with controlling your asthma.

Did you know that students can now use Inhalers and EpiPens on Campus?
(More about Hawaii Revised Statutes Chapter 302A in next week's issue)

Family Perspectives of Asthma Project

A Community-Oriented Research Partnership

What's Up This Week?

Date: June 9, 2004

Contact Hali at Ke Ola Mamo 808-848-8000 or <hrodrigues@keolamamo.org>

Interviews? Surveys? What Next?

In the Family Perspectives of Asthma Project, we will try to tell the story of the challenges of managing asthma in Native Hawaiian keiki. For the Project, the participants are the child, an adult designated as the caregiver, one sibling who is closest in age to the child, community members such as teachers and school staff, and traditional and western practitioners.

After the interviewing is completed for the family members, then it's time to begin to administer surveys. At the same time, interviews should begin with community members such as teachers and school staff, and traditional and western practitioners.

What Makes an Effective Interview?

When Discussing "Problems"

- Use notepad and list "problems" as child or parent talks
- Use your notes as prompts
- Refer to notepad and recap the stated "problem" for the participant when you reach the part of the interview that asks
  - "what are you doing about these problems"
  - Why do you think these problems happen?
- We've found that participants do not link the issues and problems they say are happening with the interview questions such as the ones above.

Young Children Like Pretend Play:

Give child a situation to anchor their answer to, such as "Let's pretend your asthma got really bad. Tell me how that would be like." (the prompts might be):

- What happens?

- Do you have to go get help?
- Do you have to do anything when your asthma gets really bad?

Strategies To Help Participants Recall:

- Hmmm, you told me that ___, ___, ___
- Why do you think think ___ happens?

Young Child: Asking For "Advice"

"Let's pretend that you are the teacher and we're in school. Pretend I asked you to teach me something about asthma, what would you say?"

Older Child: Asking For "Advice"

"Say you're the teacher and we're in school. If I asked you for some advice about asthma, what would you tell me?"

Questions Where The Child Says "Pass":

Try to rephrase or split into several questions and change to talk story ways:
For example, the original question might be:
"Do you think other children or people might feel funny or not want to do things with you?"

Try a talk story way: "Because you have asthma, do you think some people might not want to do things with you? Why? Do you think some people might feel funny when they do things with you? What about kids? Are there any kids who might not want to do things with you because you have asthma?"

We are working on a collaborative plan where other agencies, such as the American Lung Association (Big Island) will help us send out letters and flyers More next week!
A Hui Hou for now --

(Alice)

NOTES

FEEDBACK FORM

We welcome your thoughts and suggestions about the Manual. Please take a moment to fill out the form below and return it to Alice M. Tse, PhD, APRN, Associate Professor of Pediatrics and Nursing, Department of Pediatrics, John A. Burns School of Medicine, Kapi'olani Medical Center, 7th floor, 1319 Punahou Street, Honolulu, Hawai'i 96826. If you have other questions or comments, please contact Dr. Tse via email **atse@hawaii.edu** or by calling 808.983.8387.

Suggestions for Part _____:

_____

_____

_____

Suggestions for Part _____:

_____

_____

_____

Add/omit the following to/from the Manual:

_____

_____

_____

_____

Check all that apply:

☐   I plan to use the Manual to   ☐   I plan to use the   ☐   Other (describe)
    learn about research   Manual for my work

(Optional)

NAME _____

INSTITUTION _____

ADDRESS _____

_____

_____

EMAIL _____

PHONE _____