

# **Building Successful Collaborations with Researchers: A Guidebook for Community Organizations, Leaders and Members**

*A Compilation of Recommendations From:  
Community Leaders, Community Liaisons  
and Community-Engaged Researchers*

Created by:



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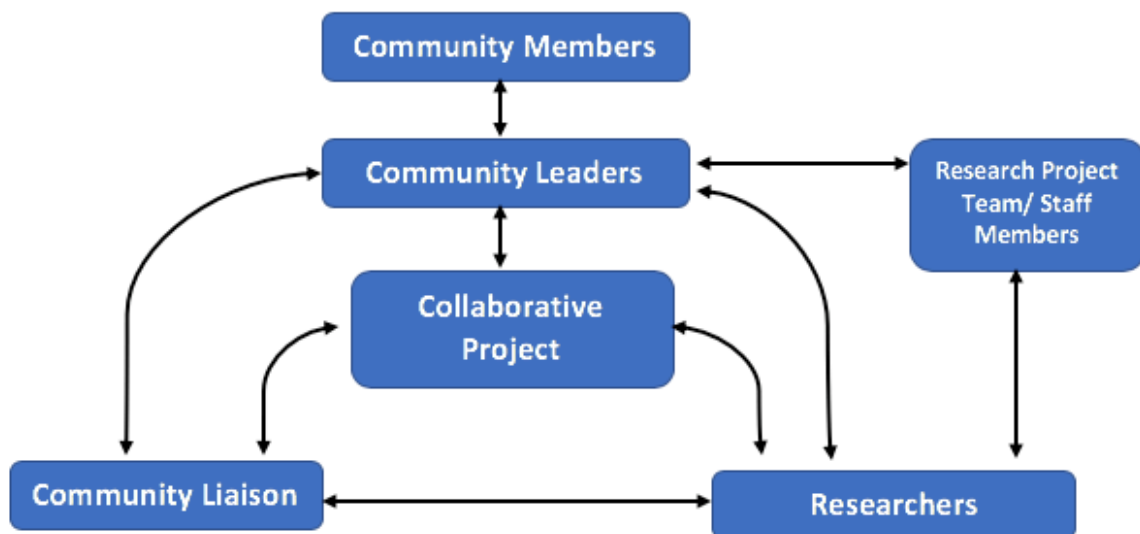
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# Introduction

Our goal in writing this guidebook is to provide community organizations, leaders and members with knowledge that will empower their collaboration as equal partners in research or other projects. The Guidebook draws on the collective experience gained by Community Faces of Utah members, community organization staff, community liaisons\* and community-engaged researchers as we have collaborated on research projects over the past eight years.

While the guidebook recommendations are primarily based on research studies and health education projects, many of the suggestions are relevant for a broad range of community-academic, community-agency and community-organization collaborations. The Guidebook has a strong focus on developing long-term relationships and partnerships. While some projects may involve shorter-term relationships, we believe the same principles of respect, transparency, equality and trust apply. The figure below illustrates a model we have used for many of our collaborative partnerships. We hope our collective experiences can provide insights and guidance for community organizations and members who seek to fruitfully collaborate with researchers, agencies or other organizations on projects.

Figure 1: Model of Bidirectional Learning and Relationships for a Collaborative Research Project



\*A community liaison is an individual who serves as a bridge between groups of people. In our work, community liaisons serve as a bridge between the research community and community organizations, community leaders and community members. They are employed by the research institution/agency/organization to facilitate relationships and partnerships between researchers and communities. They bring the voice and perspectives of community to researchers when community leaders/members are not present (such as in research team meetings) and help communities understand the perspectives of researchers. They may also be called community engagement brokers.

## Community Faces of Utah

Community Faces of Utah (CFU) is a partnership among community, university and health department organizations in Salt Lake City that is focused on improving the health of all Utahans. The group was organized in 2009 and includes the following organizations: Best of Africa, Calvary Baptist Church, the Hispanic Health Care Task Force, the Urban Indian Center of Salt Lake, the National Tongan American Society, the Collaboration and Engagement Team of the Utah Center for Clinical and Translational Science which is led by the University of Utah, and staff of the Utah Department of Health. The partnership operates on principles of mutual respect, collaboration, and shared learning.

**Vision:** CFU is a nexus of communication between resources and those who need a voice to achieve better health. CFU is dedicated to creating partnerships and engaging in opportunities for entire communities to become healthier. We work together to better provide health prevention and education for all people who face health disparities.

**Mission:** CFU makes informed, preventive health care decisions for ourselves, our families and our friends. By increasing our knowledge, we become empowered to improve health for our families and our community. We also believe that diverse community organizations and institutions can fruitfully dialogue and collaborate to build trust, learn from each other, and work together to enhance our communities' health systems.

We believe that "Together Everyone Achieves More!" (T.E.A.M.)

### *Together We...*

- Build capacity within communities
- Tailor communication within communities and partnerships
- Provide health education for communities and partnerships
- Improve health access that links communities to partners and resources
- Impact health policy that creates a healthier environment for community self-advocacy
- Work toward reducing health disparities

## Community Faces of Utah Partners

The **Best of Africa** is a non-profit 501c3, charitable organization composed of African Immigrants who live in Utah. Currently, the group primarily includes immigrants (mostly refugees) from Rwanda, Burundi and the Democratic Republic of Congo. However, all Africans are welcome and encouraged to join. Best of Africa was formed in October 2006. Its mission is to: (a) help Africans who live in Utah remember where they come from and maintain their pride in who they are. The group does this by practicing their culture, dance, food and crafts, and providing African awareness to the people of Utah. (b) Advocate for its members and connect them to different resources in terms of health, education, employment, social interactions, etc.

**Calvary Baptist Church of Salt Lake City** was organized in 1892 and provides leadership for the African American churches in Utah, southern Idaho and southern Wyoming. Calvary's mission is to ensure that everyone can reach his or her fullest potential and live a balanced life. With respect to health, the church provides exercise and cooking instruction for healthy eating, health fairs for screening and sharing information, classes on cancer prevention, exercise and healthy eating programs, eye exams, and screenings for high blood pressure and high blood sugar. While Calvary's services are predominantly used by the African American community, they are provided for all people of all ethnicities.

**The Hispanic Health Care Task Force** is a non-profit, charitable organization whose mission is to promote health and social welfare for Utah's Hispanic/Latino community. The task force was formed in 2004 and incorporated in 2005. It primarily serves the Wasatch Front but has expanded into the entire state in recent years. The task force holds educational programs for community members, trains community health workers to work on research and community projects, provides guidance for researchers and community leaders, and serves as a liaison between community stakeholders and the Hispanic community. The task force also holds an annual conference addressing pertinent issues among the Utah Hispanic population.

The **Urban Indian Center of Salt Lake** is a non-profit Title V Urban Indian Center serving the approximately 19,000 American Indians and Alaska Natives in the Davis, Salt Lake, Tooele, Utah and Weber counties. Opened in 1974, the center provides health referral services, health and disease prevention education, substance abuse prevention education, youth programs, education, cultural, and identity enrichment, and behavioral health services including substance abuse and mental health counseling.

The **National Tongan American Society (NTAS)** has served members of Utah's Pacific Islander population since 1994. The main mission of the NTAS is to create and maintain health education programs, health management and resources to decrease health disparities among children, youth, young adults and seniors. NTAS implements non-partisan civic engagement projects focusing on voter registration, citizenship workshops, encouraging public office attainment, and other civic engagement efforts that increase Pacific Islander voices on a local, state and national level. In addition, NTAS promotes education by way of workshops and scholarships. Using the CFU model, NTAS has developed multicultural ethnic coalitions, the Pacific Islander Health coalition, faith-based coalitions and others. NTAS services are available to the over 40,000 Pacific Islanders in Utah.

The **Collaboration and Engagement Team of the Utah Center for Clinical and Translational Science (CCTS)** facilitates collaborations between community organizations and academic, health care and business partners that focus on improving the health of all Utahans. The team brings to the CFU partnership its experience in community-based participatory research and in facilitating community-researcher collaborations. The CCTS is a partnership among the University of Utah, Intermountain Healthcare, HealthInsight, CFU, the Utah Department of



Health, the Veterans Affairs Salt Lake City Health Care System and the Utah Health Care Regional Network. It is a home for clinical and translational science in and among the partner institutions, across the state of Utah, and throughout the Mountain West Region.

The **Utah Department of Health** (UDOH) works to detect and prevent outbreaks of infectious disease, promote healthy lifestyles and safe behaviors, protect citizens from man-made and natural disasters, and provide access to health care for Utah's most vulnerable populations. Staff from the Healthy Living through Environment, Policy and Improved Clinical Care program actively participate in the CFU partnership.

### **Publications from CFU Collaborative Projects**

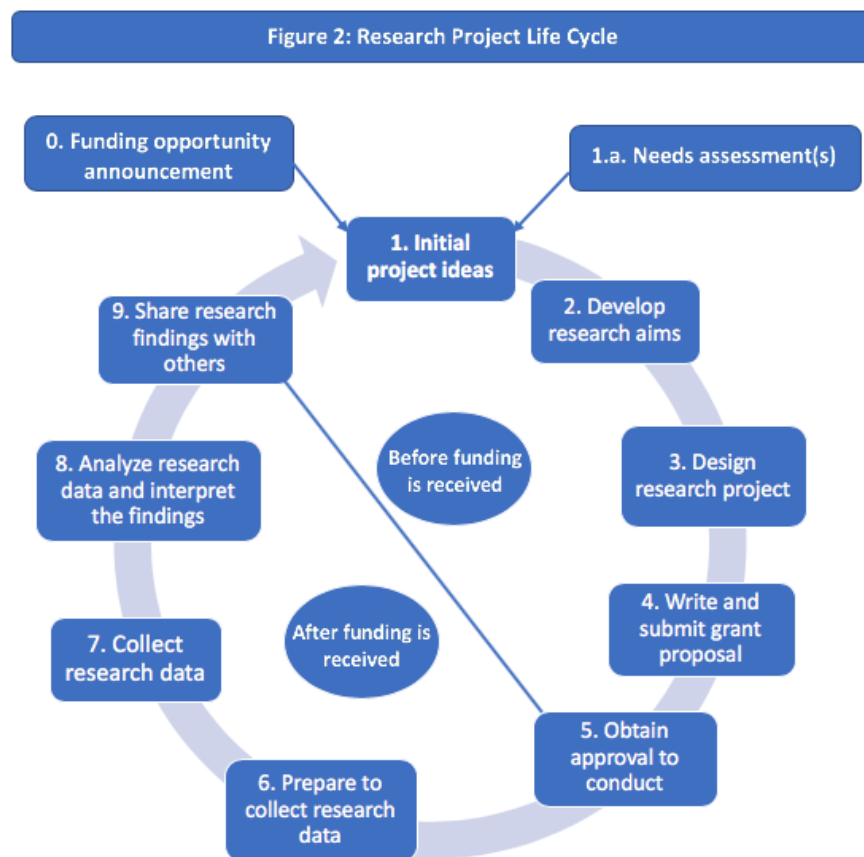
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## Guidebook Organization

The guidebook begins with an overview of the Research Life Cycle – the set of activities and processes that take place throughout a research project. This “sets the stage” for topics that are discussed in the rest of the book. Next, the Research Project Planning Guide section provides detailed information on topics to consider and discuss as you are collaboratively planning and carrying out a research project. Finally, the guidebook discusses ways to prepare for engaging with researchers and initial meetings; this section is primarily oriented toward those who are seeking to identify researchers to collaborate on a project. If your participation in a project does not involve a full collaboration, relevant sections of the Planning Guide can provide useful points to discuss when considering participation in a research study.

## Research Life Cycle

Many research projects follow a predictable set of activities, called a “Life Cycle,” shown in Figure 2. While the figure shows a one-way cycle of activities there may be one or more smaller cycles within the larger one. For example, there may be multiple rounds of steps 1, 2 and 3. Community organizations, leaders and/or members can fruitfully participate and collaborate in all phases of the Research Life Cycle.



## Before Funding is Received

**0. Funding opportunity announcement:** Many grant proposals are developed in response to a funding opportunity offered by an agency, organization or foundation. For example:

- *Federal government agencies:* National Institutes of Health (NIH), National Science Foundation (NSF) and the Centers for Disease Control and Prevention (CDC).
- *State and local agencies:* State health department and state office of education.
- *Organizations:* Alzheimer’s Association, American Heart Association and American Cancer Society.
- *Foundations:* Robert Wood Johnson Foundation and local, family foundations.

**1. Initial project ideas:** Whether prompted by a funding opportunity announcement, a need identified in the community, or a question that arose from previous research, each project begins with developing initial ideas for the project; this often involves brainstorming.

**1.a. Needs assessment:** Initial ideas for a project are often refined through gathering information. This may involve a formal or informal needs assessment conducted in the community, looking at data others have gathered and/or doing a literature search to find out what other researchers have learned that is related to the proposed project. A literature search is a search of the papers that have been published in research journals. This is usually done electronically using words related to the topic(s) of interest. For a research project to receive funding, the investigators must propose to learn something new that has not been published by others.

**2. Develop research aims:** All research project proposals include clear objectives that the researchers say they will complete by the end of the project; these may be called “specific aims” in the funding announcement. These objectives are often designed to answer testable questions posed by the project team. If the project team has an idea (based on preliminary data or other evidence) about what they think they may find, they may include a hypothesis (an educated guess), as a basis for their research objectives. The project team must propose research that will provide significant, new information that has the promise to advance knowledge about the topic.

**3. Design research project:** The project needs to be designed so data are collected to answer the research questions and/or advance understanding of the topic. People with expertise in specific areas may need to be consulted. For example, a statistician can provide information on how many research participants will be needed to determine if one treatment or program is better than another.

**4. Write and submit grant proposal:** Writing a grant proposal often involves several rounds of drafting, feedback and revision. In addition to describing what will be done to conduct the project, a proposal usually includes other components such as a budget, biographical

information about the project personnel, a description of the available facilities and resources, and letters of support.

After a grant proposal is submitted, it is usually reviewed by a panel of researchers or other individuals who have expertise in that field of research; this is called “peer review.” Usually, at least three people on the panel read the proposal, provide a written evaluation of it based on the criteria listed in the funding opportunity announcement, and score its quality. The proposals are then discussed and scored again at a meeting of the entire panel; for some funding agencies, the panel may only discuss proposals that were in the top half of the original scores. Funding agencies use the information from the review process to decide which grant proposals to fund. For federal agencies, the timeline from grant submission to receiving funding can be nine months or more.

**5. Obtain approval to conduct research with people:** If the research study will involve people, the project team must submit a detailed application to an Institutional Review Board (IRB), seeking approval to conduct the study. The IRB is composed of community members, researchers, health care providers and others. It is charged with protecting the privacy, confidentiality, rights and well-being of all people who participate in research. Usually, an IRB must approve the study before funding can be received from federal government agencies; IRB approval is required before data can be collected from research participants.

#### **After Funding is Received**

**6. Prepare to collect research data:** If they were not developed before the grant proposal was submitted, the research “instruments” must be developed before data collection can begin. These “instruments” may include surveys, interview or focus group guides, questions to measure knowledge gain, etc. Educational materials or programs may need to be developed for research participants or those who will interact with them, such as community health workers.

**7. Collect research data:** This part of the project usually takes the longest – often several years.

**8. Analyze research data and interpret findings:** Quantitative (numerical) data are analyzed to determine if they are “significant;” that is, unlikely to have occurred by chance or error. Qualitative data (for example, what people said or wrote) are analyzed to identify similarities or “themes.” For both types of data, the project team needs to consider how well and/or to what extent the data address their aims and provide answers to their research questions.

**9. Share research findings with others:** Disseminating the research project’s findings to interested people is an important part of the research process. This can be done via presentations at conferences or meetings, publications in research journals, town halls with community members, and/or stories in the media. Dissemination may take place at the end of a project or as research findings become available.

# Preparing to Collaborate on Research: Know Your Community

It is helpful if communities are prepared to enter partnerships with researchers either before they approach researchers about a collaborative project or if researchers approach them. Community leaders and community-based organization staff have these recommendations for communities as they are preparing to participate in research projects.

- Communities need to know themselves first.
- Complete a basic needs assessment to identify top community priorities. This can provide communities with a purpose for engaging in research. Suggestions for ways to conduct a needs assessment:
  - Create a survey that is distributed at a health fair or other event.
  - Hold community conversations (also known as “focus groups”).
  - Hold Town Hall meetings.
  - Bring community leaders together at a series of meetings or a retreat to identify community needs.
  - Organize community advisory boards (i.e., social justice advisory board, health advisory board, etc.) that represents different parts of the community. Each board member can collect information informally from the community and report to the board, which can then decide on priorities.
- Partner with or reach out to the local or state health department or non-profit hospital. They may have data available on their website and/or that they are willing to share. For example:
  - The UDOH provides data and reports on its website:
    - Public Health Indicator Based Information System provides information that can be searched by community, health topic and publications - <http://ibis.health.utah.gov/>
    - Office of Minority Health provides demographic profiles and reports documenting health disparities - <http://www.health.utah.gov/disparities/>
  - Search the internet using “community health needs assessment” and the location of interest.
    - State and local health departments, as well as non-profit hospitals and health care systems are required to conduct a Community Health Needs Assessment every several years, which is to guide their work in the community; these are often available online.
- Evaluate current programs your organization or others are already doing in the community.
  - Ask:
    - What is working well and why?
    - What are the challenges and why?
    - What would be the natural next steps to build on these successes?
  - Some ways to conduct an evaluation:

- Surveys, either written or verbal
  - Interviews with program leaders and participants
  - Community conversations (also known as “focus groups”)
- Prepare a “Community Snapshot” to share with researchers, this provides an overview of your community and/or the community your organization serves (*see Appendix A*).

# Research Project Planning Guide

Whether a researcher approaches you about a research project or you approach a researcher, there are many details to discuss to have a successful partnership. The Research Project Planning Guide is designed to be used by communities and researchers as they collaboratively plan a project. It may be helpful for the community organization/leaders and researchers to independently note their initial thoughts for sections of the guide and then discuss their ideas in meetings, working together to achieve harmony. While the guide is structured to be used for a multi-year project that is discussed together from the initial stages and planned as a full collaboration, relevant sections can be used for smaller projects or those in which the community is not a full collaborator in the entire project.

A blank copy of the guide is provided in *Appendix B*. A word document with the guide is available for download in Resources (right side of webpage) at:

<https://medicine.utah.edu/ccts/collaboration-engagement/>.

## 1. Project Title or Topic

- If you do not yet have a project title, it can be useful to discuss and clarify the focal topic for a project.
- If researchers/agency/organization staff contact you about participating in a project, ask them to prepare a 1-2 page summary of the project (*see Appendix C for an example*).
  - For example, the project goals/specific aims, initial ideas about what might take place (the research design) and a timeline, initial ideas on each partner's (research and community) contributions to the project, the intended benefits for each partner, and the available budget, including community partner compensation.

## 2. Project Collaborators: What are the best ways to communicate?

Name	Phone	Email	Preferred way(s) to communicate	Best days, times, and locations to meet

- Discuss each person's availability, preferred methods and times for communication, and comfort with technologies that could be used.
  - Many researchers primarily use technology to communicate with each other and may not realize that others may not have the same comfort level or access they have (such as computers at work and home with high speed Internet).
  - Share your comfort level with technologies researchers suggest and your access to them.
- *Phone*. Some individuals are available in the evening and on weekends, others are not.



- Researchers who are also health care providers may have limited phone availability during the day and may work some nights and weekends.
- *Email.* Researcher culture often involves direct, short communications, particularly in email. A brief email message or response to your email usually does not indicate anything other than the researcher was busy.
  - Clearly state the topic of your email in the subject line.
  - If you are writing about a new topic, use a new subject line; do not reply to a train of emails about another topic.
  - It is helpful to state what you are writing about in the first few lines of your email and then provide details below that. Researchers are often busy with multiple deadlines and do not have time to read all their email each day (they may receive over 100 emails each day). They will only see the subject line and the first sentence or so of emails as they scan them.
  - It may take more than one email for a researcher to respond, particularly if they are working on a deadline. Following up with a second email a few days later may prompt them to respond.
- *Sharing document files.* Researchers may suggest using online services such as Box, Dropbox or Google Docs to share files. If you are more comfortable sharing files via email or on paper, say so.
  - Ask for training in using online tools if you would like to learn how to use them. In addition to in-person training, it may be helpful to request written instructions with screen shots, particularly for online tools that you do not use daily.
- *Scheduling meetings.* Researchers may suggest using Doodle Poll or other online scheduling programs. If you are not comfortable or do not have experience using these tools, say so.
  - It may be easier to take a few minutes at the end of a meeting to set the date/time/location for the next meeting while everyone is present and can compare and negotiate calendars.
- *Meeting days and times.* In the researcher culture, meetings are usually held during business hours (Monday-Friday, 8 a.m. – 5 p.m.). Health care providers may hold meetings 7 – 8 a.m. before they begin seeing patients.
  - Share times that will work for you. This may be during lunch (as part of your lunch break), in the evening or on weekends.
- *Meeting location.* In researcher culture, meetings are usually held in their office or in a conference room in their building or one close by. However, if you are not familiar with their location on a university campus, finding parking and the building may be challenging.
  - Work together to identify meeting place(s) that will work for everyone. If your organization has an office, invite the researcher to meet with you there, perhaps every other time.



- *Videoconferencing.* While face-to-face meetings often work best, they are not always feasible. If videoconferencing is suggested as an alternative, discuss each person’s access to and comfort with this technology.
  - Conference calls are an alternative that usually works for everyone and can also be used if technology is not working.
- At each phase of a project, discuss the frequency and length of meetings needed to accomplish the work.

<b>3. Project Funder or Potential Funder</b>	
Agency/organization providing the funding	
Grant announcement name, number and web link	
Grant proposal due date	
Maximum number of years for project	
Budget guidelines	
Specific topics of interest in the grant announcement	

For grant-funded projects

- If a researcher has approached you about collaborating on a specific grant proposal, ask for a copy of the funding announcement (call for grant proposals), either a paper copy or a web link.
- Funding announcements usually list specific topics or topic areas the funder is interested in funding. They may also specify the research design or other aspects of the project.
- Some funding opportunities have a single deadline, some are due on a specific day each year, and others have three due dates each year.
- Ask the researcher:
  - The estimated timeline from grant proposal submission to receipt of the notice of award if a grant proposal is funded.
    - For proposals submitted to the National Institutes of Health (NIH), this is usually nine months or longer. Information about the likelihood of funding may be available in about six months after the grant is reviewed and scored (see #4 in the Research Life Cycle section).
  - Grant proposal success rates for this funding agency.
  - Whether or not overhead costs (Facilities & Administration; see #18 for a definition) need to be taken out of the maximum budget amount(s) listed in the funding announcement. If they will, the funds available for carrying out the project work will likely be significantly less than the amount listed.
- Be aware that grant proposals often are not funded the first time they are submitted. However, one usually receives written comments and feedback on the proposal. This

information can be used to revise and re-submit the proposal if the funding opportunity is still available.

<b>4. What are the overall goals of this project?</b>		
Community	Researchers	Shared

Examples of topics to discuss

- What do you want to accomplish?
- What community needs or issues will the project address?
- Are there short-term goals that can be accomplished within the time frame of a grant-funded project? In what ways might these contribute to achieving longer-term goals?
- If community and researcher goals are somewhat different, where is the overlap? In what ways can everyone’s goals be met?

<b>5. What strengths does each partner bring to this project?</b>		
Community	Researchers	Shared

- You are an expert on your community.
  - Successful research involving members of your community is less likely to be accomplished without your knowledge, wisdom and expertise.
  - You know the strengths, challenges, issues and needs of members in your community – both as a group and individually.
  - You know which research designs will work best and how to recruit community members for research studies.
  - Depending on your experience, you may also have experience with one or more stages in the Research Life Cycle.
- Researchers bring expertise in the stages of the Research Project Life Cycle, such as grant-writing, research design and data analysis. However, they may have less experience working with communities.

<b>6. What resources does each partner bring to this project?</b>		
Community	Researchers	Shared

- You bring multiple resources to the research partnership, such as:
  - You have access to community members to participate in the research project.

- Your organization may have staff members or know community members to hire who can carry out parts of the project.
- You may have meeting or other space needed for the project.
- Your organization may have an accountant who can handle your part of the project budget.
- Researchers are usually associated with a university or institution that provides research support such as submitting grant proposals to federal agencies, accounting services, an Institutional Review Board (needed for research involving people), secure data storage and statistical analysis of research data.

<b>7. In what ways can this project be a “win” for each partner?</b> <i>In what ways can this project build community capacity?</i>		
Community	Researchers	Shared

Examples of topics to discuss

- What are the fundamental components that need to be part of the project for it to be win-win for both community partners and researchers?
- In what ways can community capacity building and sustainability be incorporated into the project so the community gains resources in terms of knowledge and skills that can contribute to subsequent work?
- In what ways can the research/project have a positive, lasting impact on the community, helping people live better and more healthful lives?
  - Community leaders who participated in writing this guide said:
    - “Don’t do research for research’s sake. Something meaningful needs to come back to our community.”
    - “Don’t ‘harvest’ from our community. Don’t gather data from our community and leave with it.”
- How can participants be included in the project in ways that are meaningful to them and so they know they are valued as important partners?
- The community leaders who participated in writing this guide also suggested researchers could:
  - Provide quarterly health presentations in the community.
  - Develop educational programs and/or materials that are culturally and linguistically appropriate for the community and that incorporate community-appropriate visuals.
  - Provide training for community members on a topic.
  - Get health care providers at their institution to participate in a health fair.
  - Get their institution to provide sponsorship for a community event.

- For researchers who are faculty members (professors) at colleges/universities, keeping their job and advancing in their career is often primarily based on the number of grants they receive and the number of papers they publish in research journals.

### **8. What is the research design (plan) for this project?**

- What needs to take place to successfully achieve the project’s goals?
- How can the project be designed so it is congruent with both community culture and best practices in research?
- A Randomized Controlled Trial (RCT) is the “gold standard” for determining whether one program or treatment is better than another. In this type of research design, people are randomly assigned to receive one program/treatment or the other. Random assignment is like flipping a coin to decide who goes first in a game. It means no one can influence which person is assigned to each of the two groups.
  - In some RCT designs, one group participates in a new program or treatment while the other group does what they would normally do.
    - The group that receives the new program or treatment is called the “treatment” or “intervention” group.
    - The group that does what they would normally do, or receives the standard treatment is called the “control” group.
  - Some communities feel it is not appropriate for one group to receive something new while another group does not. Two possible ways to address this for programs are to:
    - Have each group receive a different amount of a new program, such as monthly vs quarterly sessions.
    - Have one group participate in the new program now and the other group participate in it later.
    - For all these options, people are randomly assigned to one group or the other.

### **9. What type(s) of data will be collected?**

- There are two broad types of data:
  - “Quantitative” data are numbers (0.5, 1, etc.).
  - “Qualitative” data are everything else. For example, words a person wrote in response to a survey question, a recording of an interview or focus group, photographs or videos.
- Common types of data collected in community-based projects include:

- Survey/questionnaire
- Interview
- Focus group
- Health data, such as height, weight, blood pressure, health history
- Demographic data, such as age, gender, race/ethnicity, zip code, employment

<b>10. If applicable: How will the research instruments (surveys, focus group/interview guides, etc.) be developed?</b>		
Community	Researchers	Shared

- One approach is to:
  - Have one person or a small team write the first draft.
  - The person or team sends the draft to everyone on the project team (including community partners). People provide input and feedback via email or in-person discussions.
  - The lead person or team revises the draft based on everyone’s input and sends it to everyone again.
  - Do as many rounds as needed to come to agreement about the instrument.

<b>11. Who will be eligible to participate in this research?</b>
<b>Who will not be eligible to participate?</b>

- Clearly define the characteristics of individuals who will and will not be eligible to participate in the research study.
  - Common characteristics for determining eligibility include age, gender, health status, and whether one has a disease or is pregnant.

<b>12. How many research participants will need to be recruited?</b>
<b>How realistic is it to recruit this number of people, given the eligibility criteria?</b>

- The number of participants who need to be recruited depends on the research study design. Often the researcher will consult a statistician to determine this number.
- Once you know the eligibility criteria and the number of people who need to be recruited, discuss with the researcher the likelihood that enough people from your community who fit the criteria will be willing to participate.

- If you have concerns, discuss ways to modify the eligibility criteria or the research study design.

<b>13. How will research participants be recruited?</b>

Examples of topics to discuss

- What methods will you use to recruit research participants? What methods will work best in your community?
  - In person?
    - Who will do the recruiting? Community Health Workers are one option.
  - Media – TV, radio, newspapers?
  - Social media?
  - Posters and fliers?
  - Other methods?

<b>14. Who will be responsible for submitting the application to conduct “human subjects” research to the Institutional Review Board?</b>	
<b>Who will need to have “human subjects” training and certification?</b>	
Community	Researchers

- In technical, researcher language, people who participate in a research study are called “human subjects.”
  - Many communities prefer to use “research participants.”
- All research involving people must be approved by an IRB before the research can begin. The IRB is composed of community members, researchers, health care providers and others. It is charged with protecting the privacy, confidentiality, rights and well-being of all people who participate in research.
- Large universities and hospitals, as well as other institutions that regularly conduct research, have IRB committees.
- The research project team must submit a proposal to the IRB that describes in detail their plans for conducting the research. The proposal includes the eligibility criteria for research participants and the number of participants, the type(s) of data that will be collected (including copies of the research instruments), how and when the data will be collected, where and how the data will be securely stored, and how the data will be analyzed. An IRB has the authority to approve, not approve or require revisions to this plan.
- For many types of research, individuals must voluntarily agree to participate in the research.

- The process of learning about a research study and deciding whether to participate is called “informed consent.”
- During the informed consent process the individual learns about the purpose of the research, the procedures that will take place if they choose to participate, how long participation will take, the potential risks and benefits of participation, alternatives to participation, the person to contact if they have questions or issues arise, their right to choose whether to participate, and their right to withdraw from the research at any time without any consequences. If they choose to participate they usually sign a document that provides this information.
  - Children ages 7-17 must voluntarily agree to participate in research. This is called “assent.” A parent or guardian must also provide “parental consent.”
- Informed consent may not be required if individuals do not provide any information that could identify them; anonymous surveys are an example. In this case, potential participants may receive a “cover letter” that briefly explains the above information and says that by completing the survey the individual indicates their consent to participate in the research
  - An IRB must determine if this process is appropriate for the research study.
- Several types of research are considered “exempt” from the requirement for informed consent. The most common exemptions are for research conducted in schools and using educational tests. Often, an IRB must determine if the exemption is appropriate.
- Everyone on the project team who will be involved in designing or carrying out a research project that involves people must receive ethics training (also called human subjects training) and be certified. This training may be online, in-person, or a combination of both.

<b>15. How and where will the project data be stored?</b>		
Community	Researchers	Shared

Examples of topics to discuss

- Where will the research data be stored and how will it be kept secure?
- Who will have access to the data?
  - Will community partners need training to access the data?
- What processes will be used to determine if someone who is not on the research team can have access to the data?
- Will community partners receive their own copies of the data? If so, in what format?
- Note that federal funding agencies may also have requirements related to data storage and access.

<b>16. Who will participate in analyzing the project data?</b>		
Community	Researchers	Shared

- In what ways can community partners participate in analyzing and/or reviewing the data?
- One approach to community involvement in data analysis is to hold a data review meeting in which researchers and community partners look at the data together and discuss:
  - Are the coding schemes/themes for qualitative data appropriate? Do these coding schemes/themes “sound” right, based on the community partners’ experiences throughout the project?
  - Are the data in tables and graphs represented in ways that are understandable to both community partners and researchers?
  - Are there further data analyses that should be carried out?

<b>17. Who will own the project data?</b>		
<i>If others want to use the data, from whom and how will permission need to be obtained?</i>		
Community	Researchers	Shared

Examples of topics to discuss

- Who will own the data from the research study?
  - Ideally, data will be jointly owned by the researchers and the community organization.
- If others want to use the data, from whom and how will permission need to be obtained?
- *Appendix D* provides an example of a data ownership and use agreement that was collaboratively developed by researchers and community organizations for a project.

<b>18. Project Personnel:</b>				
<i>What tasks are needed to carry out the project? Who will do these tasks?</i>				
<i>What training (if any) will people need? How much time will be required to do the work?</i>				
Task/Role	Community	Researchers	Training	Time

Examples of topics to discuss

- What work will be required?
- What are your best estimates of how much time will be required to do each type of work?
- Who has the expertise to do this work or can be trained to do it?



- Training community members contributes to building community capacity and sustainability.
- Will individuals need to be hired?
  - Who will hire and pay them?
  - Who will oversee them?

<b>19. What will it cost to carry out this project?</b>		
<i>(calculate the budget on a spreadsheet, keeping the following in mind)</i>		
	Community	Researchers
Personnel wages/salaries and benefits		
Research participant compensation		
Materials and supplies		
Translation <i>(if needed)</i>		
Space rental for programs <i>(if needed)</i>		
Travel to conferences		
Facilities & Administrative (overhead) Rate		

- *Personnel wages/salaries and benefits.*
  - What is fair compensation for each project team member’s time and participation in the project?
    - *Appendix E* provides example guidelines on community member compensation.
  - How will personnel who are carrying out the work of the project be paid? (for example, salary, hourly wage or by task completed)
- *Research participant compensation.*
  - What are fair amounts? Is there a previously-set community standard?
- *Materials and supplies.*
  - Will individuals who collect data need laptops or tablets?
    - Will the project purchase these?
    - Will protective cases be needed?
  - Will individuals who collect data need to connect to the Internet?
    - How will they access it? (for example, via Wi-Fi, hot spot, wireless card)
    - Will the project need to pay for Internet access?
  - Will food be needed for meetings and events?
- *Translation.*
  - In what language(s) will the project be conducted?

- Will translators be needed, such as for project materials and instruments, consent forms, or survey responses?
- Will interpreters be needed for project activities or events?
- *Space rental.*
  - Will space in the community be needed for project meetings, activities or events?
  - What is fair compensation for use of space in the offices of community organizations, churches, etc.?
- *Travel to professional (research) conferences to present the project’s work and research findings.*
  - Which conferences are appropriate for presenting the planned research?
  - What are the estimated travel, lodging, food and registration costs for each conference?
  - How many project team members (including community partners) will attend each conference?
- *Facilities & Administration (overhead) rate.*
  - Most grants allow institutions and organizations to charge a “fee” that covers costs for administration of the grant and for facilities operation and maintenance. This fee is called a Facilities & Administrative Rate Agreement (F&A Rate). It may also be called “overhead” or “indirect costs.”
  - The F&A Rate is charged as a percentage of the amount requested to conduct the research project. This amount is added to the cost for carrying out the project.
    - Universities and other organizations that regularly conduct research negotiate this fee with the federal government every few years. The fee covers expenses such as operating the grant and accounting offices, the IRB, and operating and maintaining offices and laboratory space. For universities, the rate may be ~50 percent or more.
    - Community organizations that do not have a federally-negotiated F&A Rate can usually charge a rate of 10 percent to cover expenses such as space rental, utilities, telephones, computers, Internet and photocopier/scanner/fax.
- Be aware that when a grant is funded, the budget may be cut by the funder. If so, the project team will need to discuss what changes to make in the project and the funding each partner receives.

<b>20. In what ways will the project’s findings or outcomes be shared with others?</b>	
With community members	
Conference presentations (Which conferences? Who will present?)	
Papers (Which journals?)	

What will be the requirements for authorship?	
How will authorship order be decided?	
How will presentations and papers be developed?	

- What are appropriate ways to share the research findings from the project with your community?
- Discuss and agree on the “rules” for authorship, including expectations and opportunities for all project partners. *(see Appendix F for an example of authorship guidelines developed jointly by researchers and community organizations)*
- The four criteria for authorship proposed by the International Committee of Medical Journal Editors (ICMJE; <http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html>) are:
  - Substantial contributions to the conception or design of the work; *or* the acquisition, analysis, *or* interpretation of data for the work; AND
  - Drafting the work or revising it critically for important intellectual content; AND
  - Final approval of the version to be published; AND
  - Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

<b>21. What is the timeline for this project?</b>		
Month or Quarter	Tasks	Person responsible for leading task

- How long will it realistically take to accomplish each task?

<b>22. In what ways might this project be sustainable beyond the grant funding period?</b>		
Community	Researchers	Shared

- What parts of the project may be sustainable after this grant funding ends?

<b>23. What are the expectations for collaboration/interaction beyond the end of this project?</b>		
Community	Researchers	Shared

- What are the vision and hopes of each partner for longer-term collaboration and/or interaction?

- Plan to hold a debriefing meeting at the end of the project to discuss where the partnership could go from here.

<b>25. What will we do if this grant proposal is not funded?</b>		
Community	Researchers	Shared

- Will revising and re-submitting the grant proposal be an option?
- Are there other funding opportunities that could be explored?
- Are there other researchers who might be interested in collaborating with your community?

## Identifying and Getting to Know Researchers

Researchers often are the first to approach community organizations/leaders about collaborating on a research project. However, after identifying their community's needs and priorities organizations/leaders may also want to approach researchers about collaborating on projects. This section provides suggestions about ways to identify researchers who may be interested in working with the community.

- Ask other community members/organizations about researchers they may have worked with.
  - Try to identify a researcher or staff member who has interests and a vision similar to yours and a genuine interest in your goals; this helps create win-win situations.
  - Look for researchers who are community-minded and have cultural humility.
- Attend research meetings as an observer to learn what types of research are being conducted. If/when you feel comfortable doing so, take the initiative to share your community perspective.
  - Look at the conference or meeting program to identify speakers who are presenting on topics of interest to you; try to attend these sessions.
- Many professional and advocacy organizations provide online versions of the program for their current and past annual conferences; this can be one way to identify researchers even if you are not attending the conference.
  - Google key words (such as a disease) to find appropriate organizations.
  - Some organizations only have national conferences while others also have state chapters and conferences.
    - For example, the American Public Health Association has a large, annual national conference and state chapters which hold annual conferences. Many researchers at these conferences have an interest in working with the community, so these meetings can be a good place to begin.
- Search the websites of universities and colleges near you to identify faculty members (professors) who conduct research in your area of interest; some hospitals also conduct research. Website search tips:
  - Try searching for your area of interest, typing it into the Search box on the home page.
  - Look for a list of departments and select ones that might be related to your area of interest; the list might be under “colleges and departments” (a college is an organizational unit composed of a group of related departments). The list might be under:
    - Academics
    - Programs
  - On a department home page, the list of faculty members might be listed under one or more of the following:
    - Faculty

- People
  - Research
  - About Us
- The list of faculty members may include a brief description of their research interests or you may need to click on their name or their “lab” (short for laboratory) to find their areas of interest.
- Be aware that different departments have different “cultures.” Some are more formal while others are less so.
- Look for announcements of symposiums or talks on university/college campuses that focus on your areas of interest.
  - A “seminar” or “Grand Rounds” is usually one hour long; a symposium includes talks by several speakers and may be ½-day to several days long.
  - Announcements may be on university/college websites (check the events or calendar section), in the media, or on bulletin boards.
  - Recognize that events hosted at academic institutions may be very structured and run on a tight schedule; this may be different from community culture.
- Relationships can be built over time by attending and participating in multiple events.
- Be yourself, dress in clothes that feel comfortable to you.

# Initial Contact and Meetings: Begin Building Trust

## Arranging a Meeting

- If you meet a researcher at a conference or other event, ask to arrange a follow-up meeting with them; try to set the meeting date and time right then.
- If you have not made an appointment in person, make a phone call and follow up with an email if you do not reach the person.
  - Many researchers are frequently not at their desk.
  - If the person has an assistant, you are likely to reach them.
  - It may take several phone calls and emails before you receive a response.
    - Researchers are very busy; they may have deadlines they are working to meet and may not get to their email every day.
    - Do not take lack of a response personally – multiple tries will likely catch the person’s attention.
    - It can be helpful to put your request first in an email and then provide additional information when you meet.
- It can be helpful to give the researcher five dates and times when you are available
- If you are requesting the meeting, go to the researcher’s location for a first meeting.
  - Ask for clear directions – a map, where to park, how to find the meeting location in the building and a phone number in case you get lost. GPS programs, such as Google Maps, do not always provide accurate directions for university/college campuses.
  - Allow plenty of time to find your way.

## Preparing to Meet with a Researcher

- Read the researcher’s online biography to learn more about their research and research interests.
  - Google their name or use the search function on their institution’s website.
- Come prepared with several printed copies of your Community Snapshot (*see Appendix A*).
- Be aware that researcher culture is to begin and end meetings at the scheduled time.
  - Researchers will often have another meeting scheduled right after the meeting with you.
- Recognize that the culture for many researchers is say a brief “hello” and then begin talking about the topic of the meeting; getting to know each other occurs over time.
- Recognize that both you and the researcher are experts in your own field – you are an expert on your community and the researcher is an expert in the areas he/she studies.

## During the Meeting

- Use language that indicates your interest in exploring ways to work together.

- For example: “Hello \_\_\_\_\_. I appreciate your willingness to meet with me today. I’d like to spend time getting to know each other and explore ways in which we might collaborate. I contacted you because I saw that you conduct research on \_\_\_\_\_ and thought that your interests might fit with some of ours. Let me share a bit about our community.” Give the researcher a copy of your Community Snapshot and go over the information. Talk about your community’s interests/needs with respect to research that may fit with the researcher’s interests.
- You might ask: “Now that I’ve shared this, what are your thoughts?” Begin a dialogue from here.
- Ask the researcher what he/she sees as his/her strengths and highest areas of interest.
- Discuss whether there is a potential to collaborate, addressing the needs/issues of your community and the researcher’s strengths and interests.
  - It is helpful to establish whether there is potential for collaboration in the first meeting. However, it often takes several meetings to identify a project at the intersection of a researcher’s interests/expertise and a community’s needs/interests. Be patient. Continue conversations until a good “fit” that works for everyone is identified – or until it is clear one cannot be found at this time.
  - If the researcher is not a good fit, ask whether he/she can introduce you to someone else who would be a better fit.
- Mindfully listen to the person with whom you are meeting. It may be helpful to periodically summarize what you heard him/her say so that you can both check you are “on the same page.”
- If the researcher uses language or abbreviations that you are not familiar with, ask them to clarify or define.

### **Arranging for Follow-up**

- If the researcher seems interested, arrange to follow up with them; mutually agree on a date, time and location.
- Share the meeting times that work best for you. This may be during lunch, in the evening or on weekends.
- Share the meeting locations that work well for you. If you have office space, you may wish to invite the researcher to meet with you there; this can also be part of getting to know each other.
- If the researcher suggests videoconferencing instead of a face-to-face meeting, let him/her know whether this is something you have access to and are comfortable with.
  - Conference calls are an alternative and can also be used if technology is not working.
- Discuss the best way(s) for each of you to communicate.



- Ask who the best person is for you to contact to arrange meetings or calls; this may be an assistant, program manager, research assistant, etc.

### **After the Meeting and Subsequent Communication**

- Honor the follow-up that has been agreed on and stay in touch.
  - Regularly report on progress.
  - If there is a change and something cannot be done as agreed to, communicate that to the researcher.
- It's OK to reflect on a conversation or interaction and come back with a different "take" or idea or way of looking at something; it is OK to change your mind. For example:
  - This work might be better if we did ....
  - Maybe what we discussed isn't the best way to do ....
- Invite the researcher to come visit your community, such as attend community events, church services, and other gatherings. Host them when they attend.
- Share with the researcher how they can learn more about your community, such as through social media, podcasts, community newspaper/TV/radio, newsletters.
- Recognize that it may take several meetings with a researcher or with several researchers to develop a relationship and identify a project on which you can collaborate.

Beginning with a small, achievable project can be helpful to building a long-term research partnership. This can provide an opportunity for building trusting relationships and a foundation of success.

## Appendix A: Community Snapshot

***Put the name of your organization or community here***  
*(use letterhead, if you have it)*

Address:

Contact information: *(person, phone number(s), email)*

Hours:

Leadership and staff:

Vision, Mission, and Goals:

Population(s) our organization represents/serves: *Include history/culture of the people the organization serves, if this helps in understanding the population*

Health overview of the population we serve:

*Include data for any of the seven domains of health: physical, social, emotional, occupational and financial, environmental, intellectual, and spiritual; select the ones that are most relevant to the researcher's interests*

Community health needs: *Prioritized by importance*

What we have done to address the community's health needs:

*(past, present and future plans)*

*List collaborations, partnerships, coalitions, programs; share data, if available.*

# Appendix B: Research Project Planning Guide

## Research Project Planning Guide

<b>1. Project Title or Topic</b>				
<b>2. Project Collaborators: What are the best ways to communicate?</b>				
Name	Phone	Email	Preferred way(s) to communicate	Best days, times and locations to meet
<b>3. Project Funder or Potential Funder</b>				
Agency/organization providing the funding				
Grant announcement name, number and web link				
Grant proposal due date				
Maximum number of years for project				
Budget guidelines				
Specific topics of interest in the grant announcement				
<b>4. What are the overall goals of this project?</b>				
Community		Researchers		Shared
<b>5. What strengths does each partner bring to this project?</b>				
Community		Researchers		Shared
<b>6. What resources does each partner bring to this project?</b>				
Community		Researchers		Shared
<b>7. In what ways can this project be a “win” for each partner? <i>In what ways can this project build community capacity?</i></b>				

Community	Researchers	Shared
<b>8. What is the research design (plan) for this project?</b>		
<b>9. What type(s) of data will be collected?</b>		
<b>10. If applicable: How will the research instruments (surveys, focus group/interview guides, etc.) be developed?</b>		
Community	Researchers	Shared
<b>11. Who will be eligible to participate in this research?</b>		
<b>Who will not be eligible to participate?</b>		
<b>12. How many research participants will need to be recruited?</b>		
<b>How realistic is it to recruit this number of people, given the eligibility criteria?</b>		
<b>13. How will research participants be recruited?</b>		
<b>14. Who will be responsible for submitting the application to conduct “human subjects” research to the Institutional Review Board?</b>		
<b>Who will need to have “human subjects” training and certification?</b>		
Community	Researchers	

<b>15. How and where will the project data be stored?</b>				
Community	Researchers	Shared		
<b>16. Who will participate in analyzing the project data?</b>				
Community	Researchers	Shared		
<b>17. Who will own the project data? <i>If others want to use the data, from whom and how will permission need to be obtained?</i></b>				
Community	Researchers	Shared		
<b>18. Project Personnel:</b> <i>What tasks are needed to carry out the project? Who will do these tasks? What training (if any) will people need? How much time will be required to do the work?</i>				
Task/Role	Community	Researchers	Training	Time
<b>19. What will it cost to carry out this project? <i>(calculate the budget on a spreadsheet, keeping the following in mind)</i></b>				
	Community	Researchers		
Personnel wages/salaries and benefits				
Research participant compensation				
Materials and supplies				
Translation <i>(if needed)</i>				
Space rental for programs <i>(if needed)</i>				
Travel to conferences				

Facilities & Administrative (overhead) Rate		
<b>20. In what ways will the project's findings or outcomes be shared with others?</b>		
With community members		
Conference presentations (Which conferences? Who will present?)		
Papers (Which journals?)		
What will be the requirements for authorship?		
How will authorship order be decided?		
How will presentations and papers be developed?		
<b>21. What is the timeline for this project?</b>		
Month or Quarter	Tasks	Person responsible for leading task
<b>22. In what ways might this project be sustainable beyond the grant funding period?</b>		
Community	Researchers	Shared
<b>23. What are the expectations for collaboration/interaction beyond the end of this project?</b>		
Community	Researchers	Shared
<b>24. What will we do if this grant proposal is not funded?</b>		
Community	Researchers	Shared

# Appendix C: Example of a 2-page Project Summary Prepared By Researchers for Community Partners

*Project: Value Personas and Decision-Making Strategies in Life-Threatening Illness*

*PI: Ellie Hirshberg, MD, Intermountain Medical Center*

*Funder: Intermountain Research & Medical Foundation*

## **Intermountain Health Care and Community Faces of Utah Intensive Care Unit (ICU) Project Summary**

### **Goals and Outcomes:**

We are performing a study to better understand how patients and family members experience life-threatening illness. We hope to learn community members' experience with the ICU and their perceptions of the medical community. We also want to help improve communication among the medical community, patients and families. Our long-term goal is to improve the experience of all people who have a loved one with a life-threatening illness.

We plan to publish the study findings in both poster presentations and journal articles. We welcome CFU collaboration as authors in writing and reviewing the posters and publications. We hope to expand this study into other studies that look at humanizing the ICU experience.

### **Study Process:**

There are two parts to this study – a focus group and a questionnaire/survey.

#### **Focus Group (1) that includes three members of each CFU community**

- When and Where:
  - Date: April or May
  - Time: Evening or weekend
    - At a mutually agreed upon time
  - Length: 1½ hours
  - Place: Calvary Baptist Church (standard \$100 facility usage fee provided)
  - Co-facilitated by an Intermountain team member and the Community Liaison
- Who:
  - Three individuals from each CFU community
  - Criteria:
    - 18 years or older
    - Have been a patient or had a close family member who was a patient in the ICU or Critical Care Unit in a hospital
      - The patient or family member in the ICU must have been 18 years or older
    - The hospital visit:
      - Must have lasted more than 24 hours
      - Been within the past 10 years

- Must speak and understand English

### Questionnaire/Survey

- 50 items
- Online or paper
- Requires about 30 minutes
- Available in Spanish and English
- Complete and return surveys within 60 days of CFU receiving the materials (survey begins after the focus group)
- Participants
  - 10 people from each CFU community (a total of 50 participants)
  - Receive a \$25 gift card for completing the survey
  - Participant criteria:
    - 18 years or older.
    - Must read and write in either English or Spanish
    - Share any hospital and ICU experiences, but not required

### CFU Community Leader Expectations

- Recruit three focus group members who meet the participant criteria
  - Make reminder calls before the focus group
- Review the Spanish version of the survey for clarity (appropriate CFU leader)
- Recruit 10 community members to take the survey, who meet the participant criteria
  - Administer the survey
  - Give a gift card to each person
    - Leaders will receive the gift cards with the surveys
  - Return the completed surveys to the Community Liaison within 60 days
- Each CFU community will receive \$450 for the time needed to recruit the three focus group participants, follow up with them so that they attend the focus group, and recruit 10 community members who complete the survey (estimated nine hours at \$50/hour).



## Appendix D: Data Ownership and Use Agreement

*Project: Coalition for a Healthier Community for Utah Women and Girls (CHC-UWAG)*  
*PIs: Kathleen B. Digre & Sara Simonsen, University of Utah*  
*Funding: DDHS Office on Women's Health, grant 1CCEWH111018-01-00*

### **The Coalition for a Healthier Community for Utah Women and Girls (CHC-UWAG) Collaborative Agreement**

**The Coalition for a Healthier Community for Utah Women and Girls (CHC-UWAG)** created a study that aimed to evaluate the impact of community wellness coaches on women's health behaviors in each CFU community. CFU partnered with Kathleen Digre and Sara Simonsen from the University of Utah Center of Excellence in Women's Health to do the study, and the study was funded by a grant from the Office on Women's Health (DHHS). This collaborative effort has generated data that can be used in the future by CFU as well as the Dr. Simonsen and Dr. Digre; however, such use requires permission from both groups. The goal of this Memorandum of Understanding is to be sure all parties have a say about the future use of CHC-UWAG data and that the data are prevented from being used by individuals who were not directly involved with the study without everyone's permission.

**Members.** Coalition members of the CHC-UWAG grant are the University of Utah Center of Excellence in Women's Health (Kathleen Digre, Sara Simonsen, Leanne Johnston, Pat Eisenman), Community Faces of Utah (CFU). CFU includes the following community organizations: Calvary Baptist Church, the National Tongan American Society, Best of Africa, the Hispanic Health Care Task Force and the Urban Indian Center as well as Grant Sunada, Brenda Ralls from the Utah Department of Health, and Heather Aiono, Stephen Alder and Louisa Stark from the CCTS. These partners collaborated to study the effect of community wellness coaches in communities.

**Commitment.** Members of the coalition commit to working collaboratively to accomplish the goals of the coalition. We agree to seek input from all coalition members in decisions about future use of the CHC-UWAG data and data reports. We agree to promote and participate in open discussions about upcoming publications, presentations, and grants that plan to utilize UWAG data or data reports.

**Scope.** The coalition will initiate and accept proposals for analyses, abstracts, posters, manuscripts, and presentations aligned with its stated goals.

**Collaborative Agreement Requirements.** For each separate product (analysis, abstract, poster, manuscript, presentation), coalition members will offer initial approval of the concept and will then have the opportunity to review final products prior to publication or presentation. No products will be published or presented without the consent of the members of the coalition.

**Publicity.** No member shall use the names, logos, trademarks or designs of another member in

advertising, promotions, or in any publicity, press release or other public announcement, written or oral, without the express written approval of the coalition.

Please call/write with questions or to request a form to use data contact: <contact information>

Read and Understood:

Name of CHC-UWAG coalition member \_\_\_\_\_

Signature of CHC-UWAG member \_\_\_\_\_ / \_\_\_\_\_  
(date)

Title \_\_\_\_\_

Institution/Organization \_\_\_\_\_

## Appendix E: Guidelines on Community Member Compensation

### From NIH Clinical and Translational Science Awards:

Wilkins CH, et al. Community representatives' involvement in clinical and translational science awardee activities. *Clinical and Translational Science* 6(4): 292-296. Available (free) at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3884765/>

### From the Patient-Centered Outcomes Research Institute (PCORI):

Financial Compensation of Patients, Caregivers, and Patient/Caregiver Organizations Engaged in PCORI-Funded Research as Engaged Research Partners

<https://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf>

Charter of the Advisory Panel on Patient Engagement

<https://www.pcori.org/assets/2013/12/PCORI-Advisory-Panel-Patient-Engagement-Charter.pdf>; in 2015, PCORI compensated this Panel \$1500/year.

### The Value of Volunteer Time:

This website includes an interactive graphic showing the hourly value of volunteer time for each state <http://www.independentsector.org/resource/the-value-of-volunteer-time/>

# Appendix F: Example of Authorship Guidelines for a Collaborative Project

*Project: Coalition for a Healthier Community for Utah Women and Girls (CHC-UWAG)*

*PIs: Kathleen B. Digre & Sara Simonsen, University of Utah*

*Funding: DDHS Office on Women's Health, grant 1CCEWH111018-01-00*

## **Coalition for a Healthier Community for Utah Women and Girls (CHC-UWAG) Authorship Guidelines**

### **Our Goals:**

1. All Community Faces of Utah (CFU) partners have access to the data from their community and to all data analysis results.
2. All CFU partners have the opportunity to review and approve requests for secondary outcomes analyses, and to approve all manuscripts that use CHC-UWAG data prior to publication. Examples of secondary outcomes include food insecurity, sleep, depression, gender norms, time use, etc.
3. All CFU partners have the opportunity to participate as co-authors for papers on the primary outcomes of the CHC-UWAG study and on the study design and implementation. The study's primary outcomes include the results of the CHC-UWAG Randomized Trial (goal success, diet changes, physical activity changes, weight) and the main economic analysis.
4. All CFU partners may access CHC-UWAG data for their own community and request/obtain data from all communities. All partners are encouraged to take the lead author role on secondary outcomes papers of interest.

### **Guiding Principles:**

Authorship eligibility is based on four criteria specified by the International Committee of Medical Journal Editors (ICMJE). In addition to meeting the criteria described below, all co-authors should read the entire paper, provide substantial comments (not just "I approve"), and the author should be able to describe the study, the research question addressed by the paper, and the study findings.

### **Authorship Criteria:**

The four criteria proposed by the ICMJE are:

1. Substantial contributions to the conception or design of the work; *or* the acquisition, analysis, *or* interpretation of data for the work; AND
2. Drafting the work or revising it critically for important intellectual content; AND
3. Final approval of the version to be published; AND
4. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

In addition to being accountable for the parts of the work he or she has done, an author should be able to identify which co-authors are responsible for specific other parts of the work. In addition, authors should have confidence in the integrity of the contributions of their coauthors. All those designated as authors should meet all four criteria for authorship, and all who meet the four criteria should be identified as authors. Those who do not meet all four criteria should be acknowledged.

These authorship criteria are intended to reserve the status of authorship for those who deserve credit and can take responsibility for the work. The criteria are not intended for use to disqualify colleagues from authorship who otherwise meet authorship criteria by denying them the opportunity to meet criterion two or three. **Therefore, all individuals who meet the first criterion should have the opportunity to participate in the review, drafting and final approval of the manuscript.** The individuals who conduct the work are responsible for identifying who meets these criteria and ideally should do so when **planning the work**, making modifications as appropriate as the work progresses.

When a large multi-author group has conducted the work, the group ideally should decide who will be an author before the work is started and confirm who is an author before submitting the manuscript for publication. All members of the group named as authors should meet all four criteria for authorship, including approval of the final manuscript, they should be able to take public responsibility for the work, and should have full confidence in the accuracy and integrity of the work of other group authors. They will also be expected as individuals to complete conflict-of-interest disclosure forms.

#### **Authorship Models for CHC-UWAG Data:**

1. Opportunity for direct involvement of all coalition partners for *primary outcome papers* vs. publication with some authors and CHC-UWAG Coalition listed as an author. (see \* below)
2. Publication under CHC-UWAG Coalition for *secondary outcome papers* ss. CHC-UWAG acknowledgement.
  - a. The first author should seek approval for secondary outcomes research question, allowing any community the opportunity to opt into having their data included and should provide CFU partners with at least two weeks turn-around time for approval and/or authorship (with advanced notice of review dates, if possible).
  - b. If decided up front, all CFU partners will be offered individual authorship opportunities and the final decisions will be made based upon meeting deadlines and making significant contributions.
  - c. All CHC-UWAG partners will be listed in the acknowledgements for secondary outcomes papers.
  - d. If agreed-upon up front, the CHC-UWAG coalition will be listed as the last author. (see \* below)
3. CFU may consider publishing under the CFU group name as well with support from the CHC-UWAG.

\*From ICMJE: Some large multi-author groups designate **authorship by a group name, with or without the names of individuals**. When submitting a manuscript authored by a group, the corresponding author should specify the group name if one exists, and clearly identify the group members who can take credit and responsibility for the work as authors. The byline of the article identifies who is directly responsible for the manuscript, and MEDLINE lists as authors whichever names appear on the byline. If the byline includes a group name, MEDLINE will list the names of individual group members who are authors or who are collaborators, sometimes called non-author contributors, if there is a note associated with the byline clearly stating that the individual names are elsewhere in the paper and whether those names are authors or collaborators.

**CFU Partner Responsibilities:** Opt into inclusion in secondary outcome paper proposals by deadline if so desired, read papers, and meet deadlines without multiple reminders or extensions. If co-author: provide substantial feedback by deadline, and be able to explain the study, author contributions, and specific findings to others.

**Responsibilities of academic authors working on primary outcomes:** Get feedback throughout manuscript development process including sharing data and incorporating community feedback, provide community partners with at least two weeks turn-around time to review and provide feedback on complete draft of manuscript (with advanced notice, if possible), and share/receive approval of final draft of manuscript prior to submission.

- Approval prior to submission shall include approval from all CHC-UWAG partners.
- Authors shall include all CHC-UWAG partners, either as individuals (based on contributions) or as a group author.
- All CHC-UWAG partners shall be listed in acknowledgements if group authorship is not used.

**Responsibilities of authors (academic or community) writing on secondary outcomes:** Get approval for ideas before beginning work on manuscripts (via opt in email with clear deadline), be clear at onset of the project whether authorship opportunities are being offered, share data results with all CFU partners and obtain/incorporate feedback, and obtain approval for completed work (abstract, manuscript) prior to submission.

- Approval prior to submission shall include approval from all CHC-UWAG partners.
- Individual authors may be included based on up-front agreements and contributions.
- Authors shall include CHC-UWAG as either a group author or all CHC-UWAG partners shall be listed in acknowledgements.

#### **Sample of Acknowledgement:**

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Members include:

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- Community Faces of Utah
  - Best of Africa: Valentine Mukundente
  - Calvary Baptist Church: Pastor France A. Davis, Doriena Lee
  - Hispanic Health Care Task Force: Sylvia Ricard (deceased), Ana Sanchez-Birkhead, Jeannette Villalta
  - National Tongan American Society: O. Fahina Tavake-Pasi, Ivoni Nash
  - Urban Indian Center of Salt Lake: Eru Napia
  - Utah Department of Health: Brenda Ralls
  - University of Utah and Utah Center for Clinical & Translational Science: Stephen C. Alder, Louisa A. Stark, Heather Coulter
  - University of Utah: Grant Sunada
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- University of Utah Department of Biomedical Informatics: Bernie LaSalle
- Utah State University Cooperative Extension Service:
  - Duchesne County: Suzanne Prevedel
  - Wayne County: Gaelynn Peterson
  - San Juan County: Lou Mueller
  - Beaver County: Cindy Nelson
- Utah State University Extension: Carrie Durward

**Sample of Authorship:**

Author one, author two, author three on behalf of (or in conjunction with) the Coalition for a Healthier Community for Utah Women and Girls.