

Building Successful Collaborations with Communities: A Guidebook for Researchers, Agency and Organization Staff

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

Created by:



COMPILED AND EDITED BY

Louisa A. Stark, PhD, and Heather Coulter, MEd

CONTRIBUTORS

(titles and affiliations at the time this document was written)

Community Leaders, Community Faces of Utah

- France A. Davis, Pastor, Calvary Baptist Church, Salt Lake City
- Dorienna Lee, Special Projects Coordinator, Calvary Baptist Church
- Valentine Mukundente, Executive Director, Best of Africa
- Eruera “Ed” Napia, Sacred Paths Youth Services Program Director, Urban Indian Center of Salt Lake
- Ana Sanchez-Birkhead, PhD, WHNP-BC, APRN, President, Hispanic Health Care Task Force; Associate Professor, College of Nursing, University of Utah
- O. Fahina Tavake-Pasi, Executive Director, National Tongan American Society

Community Organization Staff

- Kate Nederostek, Program Director, Alzheimer’s Association of Utah
- Sara Carbajal Salisbury, Director of Health Programs, Alliance Community Services
- Laverne Snow, Director of Toolkit Projects, Alliance Community Services

Community Liaisons

- Heather Coulter, MEd, Community Liaison, Collaboration and Engagement Team, Utah Center for Clinical & Translational Science; Member, Community Faces of Utah
- Tatiana Allen-Webb, BS, CCRP, Community Liaison, Collaboration and Engagement Team, Utah Center for Clinical & Translational Science; Member, Community Faces of Utah

Community-Engaged Researchers

- Stephen C. Alder, PhD, Professor and Vice Chair, Department of Family and Preventive Medicine Chief, Division of Public Health; Key Faculty, Collaboration and Engagement Team, Utah Center for Clinical and Translational Science, University of Utah; Member, Community Faces of Utah
- John Barbuto, MD, Adjunct Associate Professor, Division of Public Health, Department of Family and Preventive Medicine, University of Utah
- Scott Benson, MD, MPH, PhD, Assistant Professor, Division of Public Health, Department of Family and Preventive Medicine, and Division of Infectious Diseases, Department of Internal Medicine, University of Utah
- Kathleen B. Digre, MD, Chief, Division of Headache and Neuro-Ophthalmology; Professor of Neurology, Ophthalmology; Adjunct Professor, Obstetrics and Gynecology; Director, Center of Excellence in Women’s Health, University of Utah; Research Collaborator with Community Faces of Utah
- Lisa Gren, PhD, Assistant Professor, Division of Public Health, Department of Family and Preventive Medicine, University of Utah

- Eliotte L. Hirshberg MD, MS, Department of Pulmonary and Critical Care, Intermountain Medical Center; Associate Professor of Pediatrics, Division of Pulmonary Medicine and Critical Care and Division of Pediatric Critical Care, University of Utah
- Deanna Kepka, PhD, MPH, Assistant Professor, College of Nursing, University of Utah; Investigator, Huntsman Cancer Institute; Research Collaborator with Community Faces of Utah
- Anne V. Kirby, PhD, Assistant Professor, Department of Occupational and Recreational Therapies, College of Health, University of Utah
- Ana Maria Lopez, MD, MPH, FACP, Associate Vice President for Health Equity and Inclusion; Associate Director, Collaboration and Engagement, Utah Center for Clinical and Translational Science; and Professor of Medicine, University of Utah; Director of Cancer Health Equity, Huntsman Cancer Institute
- Kimberley Shoaf, DrPH, MPH, Professor, Division of Public Health, Department of Family and Preventive Medicine, University of Utah
- Sara Simonsen, Associate Professor, College of Nursing, The Annette Cumming Professor of Women's Health, University of Utah; Research Collaborator with Community Faces of Utah
- Tejinder Pal Singh, BDS, MDS, MPH, Assistant Professor, Division of Public Health, Department of Family and Preventive Medicine, University of Utah
- Louisa A. Stark, PhD, Professor, Department of Human Genetics; Director, Genetic Science Learning Center; Key Faculty, Collaboration and Engagement Team, Utah Center for Clinical and Translational Science, University of Utah; Member, Community Faces of Utah
- Grant R. Sunada, PhD, MPH, Instructor, Division of Physician Assistant Studies, Department of Family and Preventive Medicine, University of Utah; Member, Community Faces of Utah

FUNDING

Primary funding

Patient-Centered Outcomes Research Institute (PCORI) Award (EA-3957) to HealthInsight.

Additional funding

Patient-Centered Outcomes Research Institute (PCORI) Award (PCORI CDRN #1306-04912) for development of the National Patient-Centered Clinical Research Network, known as PCORnet.

The National Center for Advancing Translational Sciences of the National Institutes of Health under Award Number UL1TR001067 to the University of Utah.

The statements and views presented in this publication are solely the responsibility of the authors and do not necessarily represent the views of (a) the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee or other participants in PCORnet, or (b) the National Institutes of Health.

Index

Introduction	7
Community Faces of Utah	8
Community Faces of Utah Partners.....	8
Publications from CFU Collaborative Projects.....	10
Getting to Know the Community and Identifying Leaders	11
Recommendations from Community Leaders.....	11
Recommendations from Community Liaisons.....	11
Recommendations from Community-Engaged Researchers.....	11
Initial Contact and Meetings: Begin Building Trust	13
Recommendations from Community Leaders.....	13
Arranging a meeting	13
During the first meeting	13
Throughout interactions and relationships	13
Recommendations from Community Liaisons.....	14
Arranging a meeting	14
During the meeting.....	14
Arranging for follow-up	15
After the meeting and subsequent communication	15
Recommendations from Community-Engaged Researchers.....	16
Preparing for the meeting	16
During the meeting.....	16
Preparing to Hold a Meeting with Community Partners	17
Recommendations from Community Liaisons.....	17
Holding a Meeting with Community Partners	18
Recommendations from Community Leaders.....	18
Meeting logistics.....	18
Meeting facilitator	18
Guidelines for interacting	18
Recommendations from Community Liaisons.....	19
Meeting logistics.....	19
Meeting materials	19

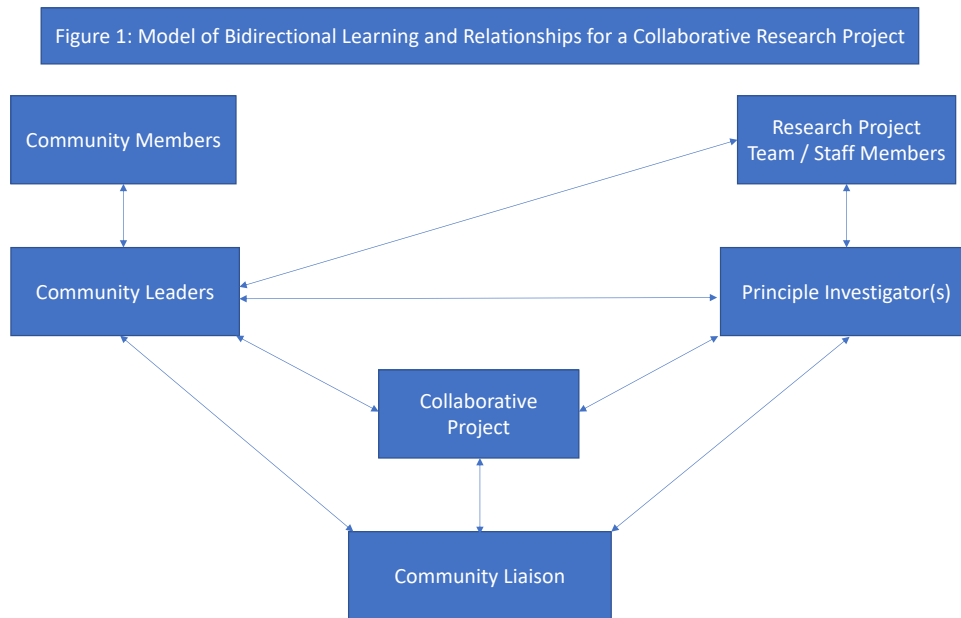
Meeting facilitator	20
Meeting processes.....	20
Expressions of gratitude	21
Recommendations from Community-Engaged Researchers.....	21
Follow-up Meetings to Identify and Discuss a Potential, Collaborative Project: Continue	
Building Trust	23
Recommendations from Community Leaders.....	23
Interactions need to be respectful	23
Show respect in these ways:	23
General principles for successful research collaborations	24
Build trusting relationships and partnerships	24
A project is “win-win” for community partners when:	25
These factors can also contribute to making a project “win-win”:	25
Things to keep in mind when collaboratively planning a project.....	25
Recommendations from Community Liaisons.....	26
Meeting participants	26
Identifying a project focus.....	26
Once the focus for a project has been identified, collaboratively discuss:	27
Recommendations from Community-Engaged Researchers.....	29
General principles for discussing and planning a project.....	29
For grant-funded projects	30
While collaboratively planning a project.....	30
Maintaining Contact While Waiting to Hear if a Grant Proposal is Funded	32
Recommendations from Community-Engaged Researchers.....	32
Collaborating Throughout a Project	33
Recommendations from Community Members.....	33
Overall guidelines	33
Guidelines for collaboration processes	33
Continually engage in building relationships.....	33
Recommendations from Community Liaisons.....	34
Working with a Community Liaison.....	34
Communication and trust-building.....	34
Project processes.....	35

Frequency of meetings	35
Scheduling meetings.....	35
Meeting content and processes	36
Progress reports	36
Technology	37
“Human subjects” training for research projects	38
Developing research/project instruments.....	38
Data sharing.....	38
Authorship on manuscripts, abstracts and presentations.....	39
Preparing abstracts for presentations about a project	39
Preparing poster presentations.....	40
Preparing for oral presentations, panel discussions, roundtable discussions, workshops, webinars, etc.	41
Writing manuscripts	41
Travel and conference arrangements	42
Attending a conference	43
Growth throughout a funded project.....	43
Recommendations from Community-Engaged Researchers.....	44
Ways to Proceed if a Project is Not Funded.....	45
Recommendations from Community Leaders.....	45
Recommendations from Community-Engaged Researchers.....	45
Disengaging from a Community When a Project Ends	46
Recommendations from Community Leaders.....	46
Recommendations from Community-Engaged Researchers.....	46
Appendix A: Guidelines on Community Member Compensation	47
Appendix B: Example of a 2-page Project Summary for Community Partners.....	48
Appendix C: Example of a Detailed Project Summary and Budget for Community Partners... 	50
Appendix D: Research Project Planning Guide	57
Appendix E: Example of Progress Report	63
Appendix F: Example of Authorship Guidelines for a Collaborative Project	68
Appendix G: Example Data Ownership and Use Agreement	72
Appendix H: Other Resources	74

Introduction

This Guidebook primarily 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. Additional insights were collected from community-engaged researchers who participated in the monthly Community Engagement Working Group, which has been co-hosted by the Collaboration and Engagement Team of the Utah Center for Clinical and Translational Science and the Division of Public Health in the Department of Family and Preventive Medicine at the University of Utah.

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 academic-community, agency-community and organization-community 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 individuals, institutions, agencies and organizations who seek to fruitfully collaborate with community organizations and members.



*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

- Davis FA, Lee D, Jones Y, Rickard S, Allen T, Napia E, Tavake-Pasi F, Nash I, Tom-Orme L, Pardilla M, Mukundente V, Goll H, Diez D, Aiono H, Drits D, Stark L. *Community Faces: A Genetics and Health Forum Project*. 2011 February. 56 pages. Available from: <http://www.genome.gov/Pages/About/OD/ECIB/2009-2010-CGF-Final%20Report-Utah.pdf>
- Simonsen SE, Digre KB, Ralls B, Mukundente V, Davis FA, Rickard S, Tavake-Pasi F, Napia EE, Aiono H, Chirpich M, Stark LA, Sunada G, Keen K, Johnston L, Frost CJ, Varner MW, Alder SC (2014). A gender-based approach to developing a healthy lifestyle and healthy weight intervention for diverse Utah women. *Journal of Evaluation and Program Planning*. pii: S0149-7189(14)00133-5. doi: 10.1016/j.evalprogplan.2014.12.003. PMID: 25559947; <http://www.sciencedirect.com/science/article/pii/S0149718914001335?via%3Dihub>
- Lai D, Bodson J, Davis FA, Lee D, Tavake-Pasi F, Napia E, Villalta J, Mukundente V, Mooney R, Coulter H, Stark LA, Sanchez-Birkhead AC, Kepka D. (2017). Diverse families' experiences with HPV vaccine information sources: A community-based participatory approach. *J. Community Health* 42(2):400-412. doi: 10.1007/s10900-016-0269-4; PMID: PMC5337438; <https://link.springer.com/article/10.1007/s10900-016-0269-4>
- Kepka D, Bodson J, Lai D, Sanchez-Birkhead A, Villalta J, Mukundente V, Tavake-Pasi F, Davis FA, Lee D, Napia E, Mooney R, Coulter H, Stark LA. (2018). Factors associated with human papillomavirus vaccination among diverse adolescents in a region with low human papillomavirus vaccination rates. *Health Equity* 2(1):223-232. PMID: 30283871 <http://online.liebertpub.com/doi/10.1089/heq.2018.0028>.
- Kepka D, Bodson J, Lai D, Sanchez-Birkhead AC, Davis FA, Lee D, Tavake-Pasi, F, Napia E, Villalta J, Mukundente V, Mooney R, Coulter H, Stark LA. (2018). Diverse caregivers' HPV vaccine-related awareness and knowledge. *Ethnicity and Health*. DOI:10.1080/13557858.2018.1562052. PMID: 30589389 <https://www.tandfonline.com/doi/abs/10.1080/13557858.2018.1562052?journalCode=cet h20>
- Drits-Esser D, Coulter H, Mannello M, Sunada G, Alder S, Davis PFA, Lee D, Mukundente V, Napia E, Ralls R, Rickard S, Tavake-Pasi OF, Stark LA. (2019). The Community Faces model: Community, university and health department partners thriving together for effective health education. *Collaborations: A Journal of Community-Based Research and Practice*, 2(1), 10. <https://collaborations.miami.edu/articles/29/>

Getting to Know the Community and Identifying Leaders

Building a new collaboration begins with getting to know a community and identifying both its formal and informal leaders (sometimes called “gatekeepers”; see more about formal and informal leaders in *Recommendations from Community-Engaged Researchers*, below). Online research, talking with others who are familiar with the community, meeting with faith-based leaders, and attending community events can all contribute to researchers/agency/organization staff gaining the knowledge, understanding and cultural humility to fruitfully connect and collaborate with community partners.

Recommendations from Community Leaders

- To identify community leaders, ask people in the community who their leaders are.
 - It is most effective to work within established community networks rather than trying to create new, externally-driven networks.
- Attend community events to become acquainted with potential community partners.
 - Recognize that some events may not begin at the advertised time and instead, may have more casual start times.
- As you are learning about the community, listen for community issues and concerns.

Recommendations from Community Liaisons

- Research the community, church or organization on the Internet.
 - Learn about the community before approaching community organizations and/or attending events.
 - Learn about the cultural practices and traditions of people in the community.
- Talk with leaders of other community organizations, community members, health department staff, faith-based leaders, other researchers or other knowledgeable individuals who collaborate with communities to identify community leaders.
- Attending community events is one way to learn about the community and begin to get to know people.
- Take the opportunity to learn about the community environment and geography while you are talking with people and building trust; e.g., where people go for medical care, grocery shopping, schools, churches, etc. Also keep an ear out for community problems, issues and concerns.

Recommendations from Community-Engaged Researchers

- Identify how a community defines itself; e.g., faith, geo-political unit, etc.
- Some communities are geographically dispersed; e.g., a community of patients who have a particular condition. In this case:
 - Start with advocacy organizations.

- Look for both formal and informal leaders/champions, community connectors, and/or community experts – these are the individuals who several people mention.
- Look for the organizations that connect with the “community” of interest.
- Researchers may need to get buy-in and/or permission from formal leaders (e.g., tribal or church leaders) to approach community members about participating in a project.
- Since many communities have both formal and informal leaders, it may be helpful to begin forming relationships with informal leaders who then can facilitate building relationships with formal leaders. Ways to identify informal leaders:
 - Observe who people look to for guidance in a meeting.
 - Hold conversations with members of the community to find out who the “go to” people are; e.g.,
 - Ask people, “When you need information about Topic X, whom do you call or with whom do you talk?”
 - For example, if Topic X is child health: “When your child is sick, whom do you call or talk with?”
 - Other examples are childcare and health care – whatever topic is relevant to the research or project.
 - Talk with multiple people. If four out of five mothers say they turn to a specific person, that person may be an informal leader for X.
- It may be helpful to begin meeting people in places where they shop, eat, play and/or pray.
- Attending community events can be a substantial way to show that the researchers/agency/organization staff value what is important to communities and are willing to learn about the community within its own environment.
- Connect with people on a personal level (e.g., sharing information about your family, interests and/or hobbies), and not just on a professional level.
- Observe and learn the intricacies of community expectations and internal relationships.
- Relationships can be built and nurtured over time through attending and participating in multiple community events.
- Remember to be yourself. For example, wear clothing that you would normally wear – not clothes that you think are similar to those of the people you will be meeting.

Initial Contact and Meetings: Begin Building Trust

Successful collaborations are built on trusting relationships between community leaders and researchers/agency/organization staff. It is essential that this trust be carefully built from the beginning and nurtured throughout a relationship. Researchers/agency/organization staff may need to take more time and a more personal approach than they are accustomed to taking in professional interactions.

Recommendations from Community Leaders

Arranging a meeting

- It may be best to request the first meeting with an individual via a phone call rather than an email since a call is a more personal form of communication.
 - Community partners appreciate it when the person requesting the meeting calls to schedule the first appointment, rather than delegating it to someone else.
- Meet with community partners at their location.

During the first meeting

- When community partners and researchers/agency/organization staff meet, begin to get to know each other by sharing stories – who each of you is as a person.
- As one faith leader said, “Selah* – pause during conversations to allow time for questions and thoughts to arise.”
 - *Selah is a Hebrew word that has been interpreted as pause/take a break/reflect.
- Ask community partners about the best way to contact them.
 - Some people use email regularly and others do not; ask which email address is preferred if someone has both personal and work email addresses.
 - Some people text and others do not.
 - Some people prefer phone calls, on their personal cell phone or land line, or on their office phone
 - Ask each person what times are best for calling or contacting them.
- Community leaders/members may find it difficult to say they are not interested in working with you because they do not want to be perceived as “mean.” Instead, they may not say anything, not respond to communications or not show up for subsequent meetings.

Throughout interactions and relationships

- Stop by and check in regularly (e.g., monthly or every other month) in person with community partners, even when it is not about something in particular; this helps build trusting relationships.
- Recognize that cultural norms may differ among communities.
- Recognize that some individuals may arrive late to meetings due to work schedules, over-scheduling or unanticipated issues.

Recommendations from Community Liaisons

Arranging a meeting

- Community partners appreciate a personal phone call from the researcher when making an initial appointment to meet.
- 30 minutes is a good length of time for a first meeting.
- Meet at a place that is convenient and familiar for the community partner.

During the meeting

- Acknowledge the community partner's expertise; i.e., someone who is an expert on their community, in a similar way as researchers/agency/organization staff are experts on their respective fields. During the meeting, verbally express appreciation for the individual sharing their expertise.
- When researchers/agency/organization staff first meet with community partners – and throughout the meeting – use language that indicates your interest in exploring ways to work together in mutually beneficial ways.
 - An example of an opening greeting: “Hello _____. I appreciate your willingness to meet with me today as an expert (and leader) in your community. I'd like to spend time getting to know each other and explore ways in which we might collaborate.”
- Begin meetings by getting to know each other; this will likely take more time than researchers/agency/organization staff are accustomed to taking for introductions.
 - Community partners appreciate it when researchers/agency/organization staff share who they are as people (e.g., family, activities outside of work), why they are motivated to do the work they do, and why they are interested in collaborating with a particular person, organization or community.
 - Ask community partners to share about themselves and their community. Examples of questions to initiate conversation:
 - “Tell me about you.”
 - “Tell me about your organization.”
 - “What brought you to this point as _____ (leader of this organization, advocate for X, etc.)?”
- As the listener, listen attentively with your eyes, ears and heart.
 - Use attentive listening techniques. For example:
 - Smile, maintain eye contact, nod to show you are listening to what the other person says and place your arms in an open position (not crossed).
 - Be mindful of the other person's body language.
 - Pause throughout the conversation to allow time for questions and thoughts to emerge; e.g., count to 10 silently.
 - Express gratitude for what the other person is sharing at least three times during the conversation; i.e., when you first meet, in the middle of the conversation and at the close of your meeting.

- When it is your turn to respond, first summarize what the other person said, reflecting what you heard, and then respond.
 - Find ways to build common ground by identifying areas of common experiences and/or interests.
- Ask questions about what the organization/community sees as its most important strengths, needs and/or issues.
- Share your interests, expertise and what you can bring to a partnership.
- Discuss whether the needs/issues of the organization/community are ones you might be able to help address through a collaboration.
 - If not, consider whether a connection can be facilitated with someone else who would be a better fit.
- Keep in mind that this “getting to know each other” process is an important, ongoing part of the relationship researchers/agency/organization staff and community partners develop together over time.

Arranging for follow-up

- If the community partner is interested in partnering or further discussion, arrange to follow up with them by a specific time; mutually agree on a date, time and location.
 - Ask the individual what the best way is to communicate with each other; e.g., “I’d like to follow up with you in a week. What’s the best way to do that – phone, email, text, Skype or an in-person meeting?”
 - Depending on the individual, Doodle Polls and emails may not be the best way to communicate about arranging meetings. In that case, a phone call may work better.

After the meeting and subsequent communication

- Honor your follow-up commitments.
 - Regularly report on progress.
 - If there is a change and something cannot be done as planned, communicate with the community partner about this as soon as possible.
- Stay in touch regularly; e.g., weekly, every other week, monthly or every other month as seems appropriate to your work together.
- During each contact with community partners, spend time at the beginning catching up with each other.
 - If it is not a planned call, begin by asking, “Do you have a few minutes to talk with me now or is there a better time later?”
 - Sincerely ask, “How are you?” – pause, and listen attentively.
 - Genuinely share how you are personally – not just “I’m fine.”
 - After these exchanges, the reason for your visit or call can be discussed.
 - Express gratitude for the person sharing their expertise, insights and time.

Recommendations from Community-Engaged Researchers

If possible, talk with community partners well before a grant submission or initiating a project. It is important that these initial discussions include conversations about ways in which a project can meet both community and research/agency needs and interests.

Preparing for the meeting

- Learn how to “do business” in other cultures.
 - The British/mainstream U.S. culture is “get down to business” quickly. Many other cultures spend time getting to know each other first.
 - Prepare for the meeting by learning how to be respectful and understand the culture of the individual(s) who will attend the meeting; e.g., the nuances of respect, hierarchy, family values, and attitudes toward time and punctuality. To do this, talk with other individuals who have worked with this community, do online research, attend community events, etc.
- Learn about the history or experience with research in the community you are approaching. There may be prior incidences of malpractice, abuse or violation of human rights that you may need to be aware of and navigate.
- Set aside adequate time for each meeting so if the meeting runs longer than expected, individuals do not need to leave early.
- Make it a priority to meet community partners in their preferred meeting location.
- Be on time for the meeting but be flexible if individuals are delayed.

During the meeting

- Interact with community partners as peers; they are experts on their communities.
- Focus on the other person and engage with her/him.
 - Leave a detailed agenda for a later meeting.
 - Be present and an attentive listener; balance this with any note taking.
 - Remember to silence cell phones to limit distractions.
- Be aware of the language you use in conversations.
 - Use a fairly formal language to show respect.
 - Use language that is accessible to everyone; avoid using jargon or acronyms.
 - Avoid using expressions that may be culturally inappropriate – learn what these might be as part of learning about the community.
 - Practice “lifelong learning” and recognize that your understanding of a community may need correction or clarification.
 - Thank community partners for their insights.

Preparing to Hold a Meeting with Community Partners

At the beginning of a collaboration, it is essential to take time to prepare community partners to participate as equals in group meetings with researchers/agency/organization staff. Over time, as the partnership becomes established and the community partners build their expertise in the research/project, less preparation may be needed.

Recommendations from Community Liaisons

- It is helpful for researchers/agency/organization staff who are proposing a research project to prepare a two-page project summary and budget (*see Appendix B for an example*).
 - Prepare the summary in an easy-to-scan format; additional pages can be added if needed for details.
 - Send the summary to participants before the meeting, but also bring paper copies to the meeting.
- Meet with individuals one to two weeks before the meeting to share and discuss the agenda items.
 - Share the meeting agenda via email or U.S. mail; follow up by phone or in person.
 - Meeting in person may support community partners in building the confidence to share their thoughts and participate fully in the meeting.
 - Plant seeds as you go through the agenda together.
 - When an individual brings up an idea or an issue ask: “Will you please bring this up in the meeting?” or “May I ask you about your idea/issue in the meeting?” This provides a reason for community partners to attend the meeting and speak up, it alerts those who tend to be quieter that you will call on them, and builds ownership, trust and equality.
 - When community partners ask a question that the partnership would benefit from hearing, request they bring it to the meeting for discussion. This supports everyone in preparing to actively participate in the meeting and contribute to jointly finding answers.
- Contact community partners at least twice before each meeting. This helps remind busy people about the meeting and often increases the number of people who attend.
 - Send everyone a group email reminder three to four days before the meeting.
 - Follow up with each individual by text/phone/email (whichever method they prefer).
 - Text message each person individually that morning; this also gives people a chance to let you know if they cannot make it at the last minute.
 - If you have not heard from a community partner and they are not at the meeting when you expected them to be, consider texting “Are you OK?” as an expression of your concern for the person beyond whether they are able to attend the meeting.

Holding a Meeting with Community Partners

Community partners need to feel equally valued with researchers/agency/organization staff. Multi-directional learning among all partners is an important element of successful meetings and partnerships. To facilitate this process, everyone needs to “check their ego at the door” and be open to new ideas and approaches. Together, the partnership can find congruency, joy and laughter through collaboration.

Recommendations from Community Leaders

Meeting logistics

- Hold meetings at the community partner’s offices or a location that is convenient for everyone.
- Discuss with community partners the appropriate and/or feasible length for meetings; long meetings may be a barrier to participation for some people.
- Begin and end meetings on time.
- Have an organized, one-page agenda; details can be provided on additional pages.
- Prepare written materials and presentations in community-friendly language; e.g., use every-day language, define abbreviations and jargon.
- Serve healthy food and water (not soda).

Meeting facilitator

- Meetings should be facilitated so everything can be discussed in the time allotted.
- Facilitator characteristics:
 - Neutral, culturally sensitive, approachable, patient, positive, and passionate.
 - Use a coaching approach that builds ownership and empowers each person.

Guidelines for interacting

- An egalitarian approach without officers may work best. Everyone around the table is an expert and brings expertise to the team’s work. Seek the approach that works best for the group.
 - It may be helpful for each person to share their expertise as part of introducing themselves at the meeting.
- Each person needs to “checks their ego at the door.”
- Multi-directional learning among all partners is important.
 - The team draws upon and learns from each member’s strengths and expertise.
 - Listening and learning from each other is an ongoing feature of successful partnerships.
- It is helpful to keep an open mind; e.g.:
 - Adapting to each other’s cultures.

- Considering new possibilities and ways of thinking.
- Being continually flexible and willing to adjust the project approaches as new ideas and experiences emerge.
- Strive to reach congruency (i.e., harmony).
- It is important for community partners to feel that their voices are heard.
 - People may be shy or reticent at first and need prompting to speak.
- Find ways to express disagreement respectfully and effectively.
 - Listen openly to what others have to say and work to understand their viewpoint.
- Share laughter and joy throughout the partnership's work; relationships are strengthened and built on these qualities.
- It is important that everyone regularly acknowledge and express gratitude for the knowledge, skill and contributions each person brings to the partnership.

Recommendations from Community Liaisons

Meeting logistics

- Hold meetings in the community at a place that is convenient for all community partners.
 - Discuss future meeting locations at the first meeting.
- Set meeting dates and times so everyone can participate; this is often easier to do in person.
- Provide healthy food and water (not soda) as the budget allows; sharing food can help build relationships.
 - Ask people if they have any food allergies or preferences.
- Arrange tables and seating to support an equitable power dynamic.
 - Sitting around a table (or tables placed in a square or rectangle) is more equitable than classroom-style seating (tables and chairs in rows) or theater-style seating (rows of chairs).
 - Check that all chairs are of equal height.
- Consider providing materials as paper handouts instead of using slides. Paper supports a more egalitarian conversation, allowing people to look at the individuals across and around them during the discussion instead of everyone's focus being on the screen.
- Assign someone (other than the facilitator) to take meeting minutes or notes.

Meeting materials

- Name tags; consider using name "tents", which can be seen around the table.
- A one-page agenda; detailed information can be on handouts or additional pages.
- Paper copies of the agenda and any other materials that will be discussed.

- White board and/or large paper and markers.
- A way for people to attend the meeting remotely, if needed; e.g., conference call line or video conferencing.

Meeting facilitator

- A non-hierarchical organizational structure works best; this supports everyone as equitable participants.
- Have a facilitator whose is skilled at engaging all participants. Their roles are to:
 - Ensure everyone’s voice has been heard on a particular topic.
 - Help balance who is speaking. If someone hasn’t spoken, invite him/her to share their thoughts; e.g.,
 - “I had a conversation with _____ last week. Would you share what we talked about?”
 - “_____, I can tell you’re thinking about this. What are your thoughts?”
 - Phrase invitations to speak in a positive way, instead of “We haven’t heard from you yet.”
 - Pause – provide time for people to think and reflect.
 - Ask questions – “How does everyone feel about this?”
 - Read people’s body language; some people may nod, etc. to indicate that they agree.
 - It is often helpful to use a white board/large paper to record everyone’s ideas and suggestions; this:
 - Provides motivation for participation; write people’s names by their ideas/comments.
 - Generates more conversation and ideas.
 - Acknowledges each person’s contributions; this can also be a subtle way of letting people who speak a lot see they are taking more of the group’s time.
 - Allows people time to read and reflect while the facilitator is writing.
 - Pause and periodically clarify what has been discussed.
 - Read what is summarized on the board, point out themes and ask for additional thoughts and/or clarifications.
- Maintain an appropriate momentum throughout the meeting. The facilitator needs to keep track of time but may also need to be flexible and adjust if more discussion seems appropriate.

Meeting processes

- Allow 10-15 minutes at the beginning of the meeting for people to greet each other, reconnect, catch up, get food, etc.
 - Welcome each person as they arrive, using culturally appropriate greeting practices that are comfortable for each person – a verbal greeting, hand shake, hug, kiss on

the cheek or touch on the arm. It may be helpful to discuss what feels comfortable for each individual or group.

- Open the meeting by welcoming everyone.
 - At the beginning and end of the meeting express gratitude and affirmation; thank everyone for their participation, their insights and their expertise.
- Have everyone introduce themselves and their affiliation; go around the table and specifically welcome anyone who is new.
 - Name and excuse those who are not able to attend – provide a reason if one has been provided and permission given to share it with the group.
- Remind everyone of the agreed upon common outcome for the meeting; constantly work toward this goal.
 - It may be helpful to ask: “Does what we’re talking about help us reach our goal?”
- Work to reach congruency (harmony) on each topic or decision; allow plenty of time to do this – it may happen within 15 minutes or it may take several meetings.
 - Dig into the details and discuss what will work best for everyone.
 - Ask what challenges might arise in connection with the ideas being discussed.
- Before ending the meeting, set up the next meeting; it is often easier to negotiate calendars when everyone is together.
 - In the early stages of a partnership, negotiation may be needed in setting up subsequent meetings; it may take several years before a consistent time and date are established.
- End meetings on time.
 - Say good-bye to each person in a culturally appropriate manner.

Expressions of gratitude

- Several times each year consider bringing a tangible expression of gratitude; e.g.,
 - Chocolate-dipped strawberries for Valentine’s Day, a poinsettia during the year-end holidays, special occasion cards with personal notes, a thank-you card, etc.
 - Offer everyone in the group the opportunity to sign cards for birthdays, a new baby, congratulations, organization anniversary or sympathy.
 - During the holidays, people may wish to bring a traditional food item to share.
- Consider hosting an open house or dinner in a group member’s home, in the park or in another place that is comfortable for everyone.

Recommendations from Community-Engaged Researchers

- While serving healthy food is preferable, you may need or wish to consider the food preferences of the people with whom you are meeting; e.g., teenagers.
- Keep any presentations succinct with time for questions and discussion with everyone who is present.

- Limit standing during the meeting by presenters or the facilitator if others are seated; e.g., talk while sitting down instead of standing at the front of the room to present. This facilitates an equitable power relationship among everyone present.
- Be aware that some community partners may be apprehensive about collaborating and/or speaking in a meeting until they are clear about the intentions and trustworthiness of the researchers/agency/organization staff.

Follow-up Meetings to Identify and Discuss a Potential, Collaborative Project: Continue Building Trust

It often takes several meetings to identify a project at the intersection of a researcher's, agency's or organization's interests/expertise and a community's needs/interests. Be patient. Continue conversations until a good "fit" that work for everyone is identified – or until it is clear one cannot be found at this time. (*see previous sections on holding meetings*)

Recommendations from Community Leaders

Interactions need to be respectful

- There are both outward and inward aspects of respect.
 - Outward manifestations of respect include greeting people, valuing their time, etc.
 - Inward manifestations of respect involve valuing people for who they are.
- Both aspects of respect contribute to building trusting relationships.

Show respect in these ways:

- Carry out interactions in ways that value each community partner's expertise, culture and contributions.
- Mindfully listen to each person.
- Recognize the cultural values and family relationship norms within each community.
- Provide appropriate financial compensation for community partners' time; if the researcher's/agency staff's time is being compensated, the community partners' time should be also. (*see Appendix A, Guidelines on community member compensation*)
- Be flexible in terms of:
 - *Communication methods.* Consider each person's preferences and technology access.
 - *The time needed to receive a response.* Recognize that community partners often have full-time jobs and other responsibilities in their lives and may need time to respond to emails, phone calls, and requests, such as for letters of support.
 - *Meeting times.* Ask about times that will work for community partners. This may be during lunch, so it is part of a lunch break, in the evening or on weekends.
 - *Meeting location.* Meet at a location that is easy for everyone to access; e.g., free parking, central location and/or public transportation options. Provide conference call or videoconferencing options if these work for the community partner.
 - *Meeting frequency and length.* Involve all partners in deciding how often to meet and the length of each meeting.
 - *The time commitment expected for the project.* Involve community partners in discussions of how much of their time will realistically be needed for involvement in the project and/or aspects of it. Discuss ways they can be involved within the

amount of time they have available; e.g., quarterly vs. monthly advisory board meetings; in-person vs. conference call/videoconference meetings.

General principles for successful research collaborations

- Be prepared to answer the question “How will this research/project help people in our community improve or live better lives?”
 - As one community leader said: “Don’t do research for research’s sake. Something meaningful needs to come back to our community.”
- Projects need to address community-identified needs and be developed collaboratively with community partners; a project needs to be designed so it will benefit the community.
- Whenever possible, work with community partners from the beginning in planning all parts of a project, from initial ideas through conducting the project, evaluation and dissemination.
 - Together, identify an achievable first project to build collaboration and success.
 - If a researcher/agency proposes a project, discuss with potential community partners whether the project would be a good fit for the community.
- The project needs to be a partnership in discovery and sharing of knowledge.
 - As one community leader said: “Don’t ‘harvest’ from our community. Don’t gather data from our community and leave with it.”
 - Work with the community to identify ways in which researchers/agencies/organizations can share knowledge the community finds useful, such as presentations about health topics, sharing project outcomes at a Town Hall or community event, etc.
- Learn who the community leaders are and support communities in building on their strengths.
 - Build community capacity so at the end of a project the community has gained resources in terms of knowledge and skills that can contribute to subsequent work.
- If possible, projects should have sustainability and help build long-term community resources.
 - As one community leader said: “Don’t just be ‘here and gone’ for a project.”

Build trusting relationships and partnerships

- Recognize that trust is built over time. In order to build this trust, projects may take longer than originally planned.
- Recognize the value of collaborating with individuals who are recognized by their community as leaders who are trusted to speak for them, represent them and make decisions on their behalf.
 - Faith-based leaders can be important partnership members.
- Respect community culture, traditions and values.

- Recognize that researcher/agency and community values and priorities may differ. Support creation of an environment that is open to multiple perspectives and recognizes that diversity is a source of collaborative strength.

A project is “win-win” for community partners when:

- Community partners and researchers/agency/organization staff come together to identify a project that meets everyone’s interests and needs.
- Community partners and researchers/agency/organization staff work together to achieve congruency – that is, walk on the same path, each with their own identity, without losing anything by participating in the partnership.
 - Everyone involved needs to “check their ego at the door” when interacting.
 - Together, celebrate each other’s differences and what each partner brings to the partnership.
- Shared learning is continuous and multi-directional.
- Everyone listens and learns from each other.
- The partnership values the strengths and expertise of each partner.
- The project includes the participants in ways which are important to them.
 - Participants are valued as important partners in the project.
- The project has a positive, lasting impact on the community and families.

These factors can also contribute to making a project “win-win”:

- Improved health, preventative health care, and/or accessible health care resources for the community or other means of improving community members’ lives, particularly on a sustainable basis.
- Community education that is part of a project.
- The project may impact policies that matter to the community.

Things to keep in mind when collaboratively planning a project

- Recognize that it takes time to begin a partnership and collaboratively plan a project. This process may take longer than anticipated.
- Everyone needs to be an owner in the project; i.e., everyone needs to be invested in and own the design, processes, data and findings.
 - People are motivated to participate in a project when they feel they have a role in it; As one community leader said: “The ‘researched’ become the researchers.”
 - When community partners provide input on a project, the project and outcomes may look different than originally conceived and may be better.
- Recognize that engaging appropriate community partners in the project processes (such as collecting survey data) is very important.

- For example, if a researcher/agency staff hands out a survey, community members may fill it out quickly. When a survey is offered by a trusted community member, participants are more likely to think carefully about their responses.
- Community partners need to be involved in analyzing and interpreting data.
- A system for storing the data, deciding who has access to it and who can use it needs to be carefully designed and agreed on by everyone involved in the project – including community partners – so the data will be protected.
 - External funding agencies may have requirements that also need to be followed.
- Disseminating the project work and outcomes is very important – just as important as developing and conducting the project. The ways the data are disseminated need to be based on a collective decision and be culturally appropriate.

Recommendations from Community Liaisons

Meeting participants

- Discuss with community partners if/when it is appropriate to bring other community partners into the conversation.
- Bring additional members of the research/agency team to follow-up meetings, when appropriate, so everyone can be involved in the discussions.
 - Consider balancing the number of research/agency team members with the number of community partners to maintain a feeling of equality; it is OK to have more community partners than research/agency team members in meetings.
 - When new individuals first participate in a meeting, repeat a shorter version of getting to know each other (see above).

Identifying a project focus

- When possible, identify the project focus together with the community partner(s).
- It may take several meetings to collaboratively identify a project that addresses a community need and is a fundable research question(s) or project.
 - For example, discuss what the most pressing needs are in the community (e.g., diabetes, mental health, heart disease, cancer, food insecurity) and the expertise and interests of the researcher(s)/agency staff.
 - See the *Holding a Meeting with Community Partners* section for guidance on facilitating a collaborative conversation.
- 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.
- If the researchers/agency/organization staff have ideas for a project for which they are seeking community involvement, prepare a one to two-page draft summary of initial ideas for the project (*see Appendix B 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. *(see Appendix B for an example)*
- Use language that can be understood by all partners.
- Use bulleted statements or other techniques to allow for easier scanning.
- Ask the community partner how they would prefer receiving the summary before the meeting; e.g., U.S. mail, email, fax.
- If the community partner expresses interest in a project, prepare and share a more detailed description and budget *(see Appendix C for an example)*.

*Once the focus for a project has been identified, collaboratively discuss:
(see the Research Project Planning Guide in Appendix D to guide your discussions)*

Fit: What about the project would make it a good fit for this community partner?

- In what ways can community capacity building and sustainability be incorporated into the project from the beginning?
- What are the fundamental components that need to be part of the project for it to be win-win for both the community partners and researchers/agency/organization?

Success: What is the “currency” of each member of the team? In what ways can the project be a “win” for everyone?

- For researchers, this may be grant awards, publications and presentations.
 - Be clear about the extent to which authorship order matters to each person.
- For community partners, in addition to the factors listed above (in the Recommendations from Community Leaders about “win-win” projects), this may include:
 - Quarterly health presentations in the community.
 - Development of educational programs and/or materials that are culturally and linguistically appropriate for the community and that incorporate community-appropriate visuals.
 - Training for community members on a particular topic.
 - Researcher/agency/health care system participation in a health fair.
 - Providing sponsorship and or assisting with a community event.

Team: Who needs to be involved in designing the project?

- For example, a team might include community leaders/champions from each community involved, a community liaison, the principal investigator and one to two project staff *(see Figure 1 on page 7)*.
- It can be helpful to have at least two community leaders/champions so there is always at least one community representative at each meeting; people may not always be able to attend or may have life/work changes that impact their ability to participate.

Project design: How can the project be designed so it is congruent with both community culture and best practices in research?

- What needs to take place to successfully achieve the project’s goals?
- If a randomized controlled trial or a closely matched comparison study is a possible design, explain the design and the type(s) of research findings it supports; discuss whether the community partner feels the design is appropriate for their community.
 - For example, the community partner may feel it is inappropriate to have one group that does not receive anything (the control) while another group receives something (the intervention). Two possible ways to address this are to:
 - Have differing “doses” for each group, such as a monthly vs a quarterly intervention.
 - Utilize a delayed intervention design in which one group is randomized to receive the intervention first and the other receives it at a later time.

Project data: How will data be shared between the community partners and researchers/agency/organization? *(see Appendix G for an example of a data use agreement)*

- Who will own the data from the project? Ideally, data will be jointly owned.
- Where will the data be stored? Will community partners receive their own copies of the data? If so, in what format?
- How will data be triangulated with community partners?
- In what ways will data be shared with the community partners?
 - Researchers may want to provide several suggestions to initiate discussion with community partners as everyone jointly decides what approach(s) will work best.

Personnel: Who will carry out the work needed to conduct the project? Collaboratively discuss:

- What work will be required?
- 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? How will they be paid (e.g., hourly or by task completed)?
 - *(see Appendix A, Guidelines on community member compensation)*

Time commitments: How much time will community partners need to spend on the project?

- Estimate the time that will be required.

Resources: What resources will be needed to carry out the work of the project?

- In what language(s) will the project be conducted and data collected? Will translators and/or interpreters be needed? If so, who will do this and how will they be paid?

- What materials and supplies will be needed?
- Will individuals who collect data need laptops? If they will need to use the Internet, how will they access it? (e.g., via Wi-Fi, hot spot, wireless card)
- What space will be needed? (e.g., meeting, office, etc.)

Budget: How can a budget be developed that fairly compensates everyone for their time and participation in the project?

- The budget needs to be transparently negotiated between community partners and researchers/agency/organization staff.
- Researchers/agency/organization staff may need to investigate their institution’s rules and guidelines for subcontracts, community grants, consulting agreements and compensation.
- Subcontracts or mini-grants need to be openly discussed and negotiated.
 - Community partners may need funds to hire staff.
 - Include overhead for community organizations. If they do not have a federally-negotiated Facilities and Administrative (F&A) rate, they can usually charge 10 percent.
- Find out from each community partner if the subcontract, grant, consulting agreement or compensation will go to an organization or to an individual.
- Community partners need to be fairly compensated for their time and participation in the project.
 - What are the hourly rates for each person who will lead and participate in the project? (e.g., community leaders, community project coordinators, community health workers)
 - Paying individuals by the specific work task carried out instead of hourly is an option.
 - What are the community “norms” for participant incentives such as for focus groups, surveys, etc.?
 - Guidance from other organizations may be helpful. (*see Appendix A*)
- Include funds to cover travel and registration expenses for community partners to participate and/or present at conferences.

Recommendations from Community-Engaged Researchers

General principles for discussing and planning a project

- Consider the topics or issues that communities would like researchers/agency/organization staff to address. Be prepared to respond to the question: How will this research benefit our community?
- Discuss as a team what each partner (research and community) needs for the project and the associated research activities to be successful for all partners.
 - It is helpful for both researchers/agency/organization staff and community members to discuss their expectations when planning and before starting a project.

- Timely communication and adjustments may need to occur during the project if these expectations need to change.
- Identify terminology that needs to be defined or explained to ensure communication is effective between researchers/agency/organization staff and community members throughout the research process from planning through publication; be aware of using acronyms and jargon.
- Reach out to community partners as soon as possible when planning a grant proposal and provide adequate time for discussing and revising the proposal and obtaining letters of support.

For grant-funded projects

- If the proposed project is responding to a specific call for proposals that limits the research design or other aspects of the project, be clear about this with community partners; share the funding announcement.
- Share how grant funding “works” with community partners, including:
 - The long timeline from grant proposal submission, to proposal review, notice of funding status and receipt of funds.
 - The grant proposal success rates for the funding agency to which you are applying.
 - The frequent need for resubmission.
 - The possibility that the budget may be cut if the grant is awarded.
 - The overhead (Facilities & Administration) rate for each institution/agency/organization that is involved in the project. For some federal agencies, overhead comes out of the maximum grant funding listed in the program announcement/request for proposals/funding opportunity.
 - That one person may need to be listed as the Principle Investigator even when the project is a collaborative, group effort.

While collaboratively planning a project

- Determine meeting times and processes that balance respecting researcher/agency/organization staff and community partners’ time and the need to be timely in planning the project/proposal.
- Engage community partners in discussions of the research plan and in formulating (if possible) a long-term strategy for sustaining community improvements once a project is completed.
- Share each draft of the research plan with community partners, allowing time for each person to provide input and feedback.
- When negotiating the budget, remember community leaders need to be compensated for the time they spend working on the project as consultants, advisory board members, community facilitators, etc. (*see Appendix A*)

- Clarify with community partners ownership and planned uses of the study data. (*see Appendix G for an example of a data use agreement*)
- Discuss with community partners ways in which they will participate in analyzing and interpreting the data and ways in which the data will be shared with community participants.
- Discuss and agree on the “rules” for authorship, including expectations and opportunities for all collaborators. (*see example in Appendix F*)
- Discuss which activities are dependent on grant funding and which will continue after the project funds have been expended. Determine roles and responsibilities for next steps after the planned project has concluded.
- Discuss what the collaborative team will do if the grant proposal is not funded.

Maintaining Contact While Waiting to Hear if a Grant Proposal is Funded

It often takes six to nine months or more from the date a grant proposal is submitted until a definitive funding decision is made by the agency to which it was submitted. During this time, it is important to maintain contact and continue building a trusting relationship with community partners.

Recommendations from Community-Engaged Researchers

- Maintain contact with community partners after a grant proposal submission; e.g.,
 - Continue to attend and support community events. Ask community members which events matter most to them and make an effort to attend these.
 - Sponsor a family for Christmas or another holiday.
 - Be clear if this is something you (as an organization or individual) may be able to do one year but not necessarily on an ongoing basis.
 - Contribute to community/organization fund drives.
 - A Community Liaison can check in monthly with the researcher/agency staff and community to update the community.

Collaborating Throughout a Project

Throughout a collaborative project, it is essential to continue building and maintaining the trust that was initiated while planning the project. In order for a project that involves community members to be successful, the trust that was built with community partners/leaders will need to be extended to the broader community. This requires careful attention; trust can easily be diminished or destroyed. Working together in ways that are respectful and fully transparent are critical parts of this process.

It is important to be flexible and open to changes throughout a multi-year collaborative project with communities. Circumstances and people's lives change. A willingness to work together to find solutions to challenges will help the project move forward and may lead to unexpected, positive results.

Recommendations from Community Members

Overall guidelines

- “Our work together should be continually evolving.”
- “Learn and want what is best for our community throughout a project.”
- “If you know the people and value the community more than the project, then the community will make an investment when researchers/agency/organization staff request assistance with a survey or other part of a research project.”

Guidelines for collaboration processes

- Recognize that community partners often have full-time jobs and other responsibilities and may need time to respond to requests, emails, phone calls, etc. (*also see “Show respect in these ways” in Follow-up Meetings section, above*)
- Face-to-face meetings are best, particularly at the beginning of a project; it can be challenging to develop a relationship over phone, text, email or video-conferencing.
- Written progress reports, completed by both community partners and researchers/agency/organization staff, provide a context and guide for conversations on how the project is progressing. (*see example in Appendix E*)
 - Debriefing meetings with community partners can also be an effective way to discuss the progress of a project.

Continually engage in building relationships

- Examples of ways to continually develop relationships include:
 - Hold informal partnership events, such as an open house or meal at someone's home or in the park.
 - Develop and maintain relationships with a broad range of community members.
 - Attend community events; e.g., pow wows, health conferences, dinners, holiday events and celebrations.

- Recognize that relationships require conversation and time to hear each other; discuss similarities and celebrate differences. Understanding is developed through ongoing communication.
- Find ways to support community partners in mentoring the “next generation” of community leaders so if they are not available (have to step aside, are out of town, have a health issue), there are others who can participate in and/or continue the work.

Recommendations from Community Liaisons

Working with a Community Liaison

- A skilled Community Liaison can facilitate community-researcher/agency/organization partnerships; e.g.,
 - Participate in all research/agency/organization team meetings to bring the voice of the community when they are unable to attend and bring the voice of the researchers/agency/organization to the community.
 - Advocate for the community in research/agency/organization team meetings and advocate for researchers/agency/organization staff with community partners.
 - Inform the research/agency/organization team when a community partner has an illness (self/child/family member), a death in the family, an accident, other work obligations, etc. that impacts their ability to carry out planned responsibilities and/or meet deadlines.
 - Provide input/feedback on research instruments as a first step in making them “community friendly;” e.g., appropriate literacy level, culturally appropriate, etc.
 - Help create new strategies within the research/project process, as needed.
 - Set up a three-way call with researchers/agency/organization staff and community partners if something needs to be addressed immediately.
 - Follow up with community partners on topics that arise in research/agency team meetings.
 - Talk with community partners weekly to check in.
 - Revise emails drafted by researchers/agency/organization staff so they are in “community friendly” language.
 - Prepare everyone for the next meeting.
 - Constantly reflect with researchers/agency/organization staff and community partners on the community engagement process and how it is evolving throughout the project.

Communication and trust-building

- Continual building of trusting relationships between community and researcher/agency partners is needed throughout a project.
- Expressions of gratitude are always appreciated; e.g., holiday gifts, birthday or other special occasion cards signed by partnership members, etc.
- Attend community events that are not directly related to the project.

Project processes

- Remember that for community partners, the project is not their full-time job; participating in the project needs to be as easy, accessible and efficient as possible.
 - Community partners may need to work on the project in the evening or on weekends.
- Be aware that for some community partners, expectations written in an email may not come across the same as in person and may not be attended to in the same way.
- Be willing to continually evaluate and reflect on the project processes. The process is just as important as the project; a transparent process that includes open communication and flexibility, allows the project to proceed.
 - Self-reflection is critical; e.g., “What can **we** do to improve this process so the project can be carried out successfully?”
- Focus on the positive strengths of community partners and build on them while also addressing any challenges that arise.
 - Challenges can often be addressed via a transparent conversation in person or on the phone. If working with a Community Liaison, involve them in the process.

Frequency of meetings

- At the beginning of a project, hold a project kick-off meeting with all partners – it may have been months since the grant/project proposal was submitted. Review the project aims, design, budget, etc. (*see sections on “Preparing to Hold a Meeting with Community Partners” and “Holding a Meeting with Community Partners”*)
- At each phase of a project, discuss the frequency and length of meetings needed to accomplish the work.
 - In the initial phases of a project, more frequent interaction (such as weekly or bi-weekly meetings, calls, and/or emails) may be needed as the project team continually builds their relationships, identifies each other’s needs and develops ways to respond to them.
 - It may be possible to hold some meetings in connection with a regularly-scheduled community meeting.
 - Conference calls or videoconferencing may be possible for some meetings once trust and connections are established.

Scheduling meetings

- Videoconferencing technology (e.g., GoToMeeting, Skype, Zoom, etc.) may not be accessible or work for all community partners; telephone calls may be most accessible for everyone.
- Using Doodle Poll or other online services to schedule meetings may not work for community partners; ask about each person’s internet access and comfort with using online meeting scheduling methods.

- Scheduling meetings in person with everyone present often works the best so that people can negotiate the day and time.

Meeting content and processes

- Meetings are an opportunity for everyone to stay current on what is happening with the project, celebrate successes, what is working well, and discuss challenges and how to address them.
- Begin calls or meetings with chatting about what is going on in people’s lives before getting to “business.”
- Remind community partners about the project goals, aims and objectives, and design; these are not part of their daily lives. It often takes quite a while for community partners to begin to remember all the project details since they may not “live and breathe” them as researchers/agency/organization staff do. It may be helpful to review the project framework every quarter.
 - Depending on the project and its design, it may be helpful to review topics such as: the concept and implementation of randomization; differences between quantitative and qualitative data; what it means to aggregate data; why the funder requires regular reports and the content of these reports; how community and project reports are linked to funding; why evidence of human subjects training (e.g., certificates of completion for CITI and HIPAA training) is required.

Progress reports

Regular progress reports are one way to foster community-researcher/agency staff communication throughout a project (*see Appendix E for an example*). It is helpful for all partners to agree on the frequency of these reports (such as quarterly) and their content at the beginning of a project. Community partners note it is important to them that these reports not entail a large amount of additional work.

- Progress reports provide an opportunity for self-evaluation and partner evaluation and facilitate one-on-one community partner-researcher/agency staff discussions outside of whole group settings.
- The report can include questions such as the following, which each partner responds to separately and then discusses together in a meeting:
 - What was successful for the project this quarter?
 - What was challenging with the project this quarter?
 - What could be improved for next quarter?
 - What are our goals for the coming quarter?
 - The community partner sets goals for itself and the researchers/agency/organization staff set goals for themselves.
- Progress reports also can include sections for:
 - Tracking different types of project activities.
 - Tracking the meetings community leaders or others are attending.

- Attendance numbers at events.
- Ways in which the project is being shared in the community, etc.
- Progress reports can provide a mechanism for budget tracking; e.g.,
 - Itemized community partner expenditures for the quarter.
 - The amount of time spent by the community partner (or individuals they employ) on the project.
- Progress reports can provide a mechanism to manage disbursement of project funds; i.e., a progress report must be submitted and the meeting to discuss it must take place before funds are disbursed for the next quarter.
 - During the meeting, everyone signs off on the report, and an invoice is signed for work completed during the previous quarter. Both the community partner and the researchers/agency/organization receive a signed copy of the report for their records.

Technology

- Recognize that community partners and members may not have computers or internet access in their homes or cell phones with unlimited minutes and a large data plan.
 - Computers at the library may time out, resulting in all unsaved data being deleted, such as from CITI training, surveys or data entry for the project.
 - One option is to provide a laptop, iPad and/or mobile hotspot device (for Internet access) for everyone who is collecting and entering project data.
 - If the project provides technology, have a signed agreement with everyone that describes handling of potential issues such as breakage, malfunction or loss. Also, detail what will happen with the device(s) at the end of the study.
 - Provide protective cases for laptops and mobile hotspot devices.
- Sharing files via technology (e.g., Box, Dropbox, Google Docs) may not work for everyone; ask what tool(s) everyone is most comfortable using.
 - Training in using online tools may need to be provided.
 - Some individuals may not feel comfortable using a tool even after training; emailing documents as attachments may work the best.
 - Hand delivery or mailing hard copies may be another option.
- Using Doodle Poll or other online calendar scheduling programs to schedule meetings may not work for everyone.
- Using SurveyMonkey, REDCap or other survey software may not work for community partners; ask whether this option will work for community members.
 - The person administering surveys may need:
 - The ability to provide technical support to individuals taking an online survey.
 - To read each question and the response options to an individual in person or on the phone.

- Paper surveys distributed during an in-person meeting may work best.

“Human subjects” training for research projects

- The use of “human subjects” and “research subjects” may be offensive to many community partners; “research participants” is more inclusive.
- A research team member may need to introduce “human subject” protections and the Institutional Review Board (e.g., what the IRB is and how it operates) for community partners.
- Explain why training in Responsible Conduct of Research (RCR) is needed and important for all members of the research team.
- Online RCR training such as CITI (<https://about.citiprogram.org/en/homepage/>) and HIPAA (Health Insurance Portability and Accountability Act) can be very frustrating for community partners.
 - A research team member or a Community Liaison may need to assist community partners in person or via the phone in setting up a username and password for each training and in accessing the trainings.
 - It can be helpful to provide community partners with detailed instructions for doing this.
 - It may be helpful to work through several modules together so the community partner understands how the online training works.
 - Continue to have someone available via the phone as questions arise.
 - Provide instructions for printing the completion certificates or saving them to a computer desktop so the certificates can be sent to the researchers/agency/organization staff.
- The Community Partner Research Ethics Training (CPRET) and Certification, developed by the Clinical and Translational Science Institute at the University of Pittsburgh, provides a model for training tailored to a specific study that can be used as an alternative to RCR/CITI training; <http://www.ctsi.pitt.edu/research-community-cpret.html>

Developing research/project instruments

- Discuss who will write the first draft of research/project instruments (e.g., surveys, interviews, focus group guides, etc.) and make revisions.
 - Share each draft with everyone on the project team (including community partners) for input and feedback via email or in-person discussions.
 - Revise each draft based on everyone’s input and share it again.
 - Do as many rounds as needed to come to congruency about the instruments.

Data sharing

- Suggestions for preparing community partners to participate in a data review meeting:
 - Send the data prior to the meeting so each community partner has time to review it and ask questions.

- If working with more than one community partner, schedule an in-person meeting with each partner one to two weeks before the whole-group meeting to discuss the data.
- During both the individual and whole-group meetings, discuss and review all data analyses.
 - 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?
 - Review tables and graphs. Are the data represented in ways that are understandable to both community partners and researchers/agency/organization staff?
 - Are there further data analyses that should be carried out?
- After the meeting:
 - Invite the community partners to send their follow-up thoughts.
 - Look at the data analysis and representations in light of community feedback and adjust the visualizations, if needed, so they are understandable to community partners.

Authorship on manuscripts, abstracts and presentations

- Collaboratively discuss authorship and agree on the criteria for authorship. (*see Appendix F for an example of jointly developed authorship guidelines*)
- 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.
- For meeting these criteria with community partners, consider both written and oral contributions.
- Collaboratively discuss and agree on author order for each manuscript, abstract, presentation, etc.
 - Guidelines for authorship from professional societies or journals can provide information about the contributions that are required to be included as an author and how author order should be established.

Preparing abstracts for presentations about a project

- Discuss the abstract topic, content and type of presentation at an in-person meeting with community partners.

- Provide example abstracts from the conference to which the abstract is being submitted.
- Discuss the data that will be included in the abstract.
 - This is a good time to review the data and what it shows.
 - Provide copies of the data, including ways to visualize it, such as in tables, graphs or other figures.
- Together, determine who will write the first draft.
- Email back and forth and/or have phone calls to edit the abstract, making sure everyone has input.
- Include everyone who played an important role in conducting the project as an author, both researchers/agency/organization staff and community partners.
- Decide who will be responsible for submitting the abstract; be clear about the deadline.

Preparing poster presentations

- Discuss the poster content at an in-person meeting.
 - Provide example posters and discuss good poster design.
 - Jointly discuss and decide how data (e.g., figures, tables) will be displayed.
 - If photos of community members and/or community events will be used, ensure written permission from individuals in the photos is on file.
 - Discuss the logos that will be included on the poster.
 - If the poster is being prepared by community partners:
 - Focus on the community's strengths.
 - Provide constructive feedback and suggestions.
 - Provide a PowerPoint template to use in preparing the poster.
- Follow up in-person, or via email and/or phone; it may take several rounds of revision to finalize the poster.
- Prior to printing, have an in-person meeting with all the authors for final review of the poster and to practice the presentation.
 - Email a PDF of the poster to the authors prior to the meeting.
 - At the meeting, project the poster and/or have paper copies for discussion.
 - People can take notes on the hard copies and give them to the person who will make edits to the poster; this facilitates everyone's voice being heard.
 - Have the people who will be involved in presenting the poster practice their presentation.
 - Provide guidance on how to give a poster presentation.
 - Discuss who will be responsible for printing the poster and who will pay for the printing.
 - Coordinate the logistics of presenting the poster:
 - Who will bring the poster to the meeting?

- What handouts will there be at the poster presentation? (e.g., business cards, 8.5 x 11" copies of the poster to hand out, a flier about the partnership, etc.)
- It is often easiest for the researchers/agency/organization staff to arrange and pay for the poster printing.
 - Fabric posters may be more convenient for travel.

Preparing for oral presentations, panel discussions, roundtable discussions, workshops, webinars, etc.

- Collaboratively, in-person, discuss the presentation format and content.
 - Discuss the amount of time available and plan how the time will be allocated.
 - Ensure that community voices are represented and heard via the presentation format, photos, quotes, etc.
- Follow up with emails and phone calls to refine the presentation.
- Hold an in-person meeting to finalize the presentation and presentation responsibilities, and to talk through or practice the presentation.

Writing manuscripts

- As part of a discussion with community partners about the project data, the researchers/agency/organization staff can point out data that would support topics for manuscripts. Through conversation, the team can decide on the manuscripts they will work on together.
- Once topics have been identified, decide who (individual, pair or small group) will draft each manuscript or section of a manuscript.
- To refine a manuscript draft, the following process is helpful:
 - The first author(s) compiles the first draft of the manuscript.
 - The first author(s) sends the draft to all authors, providing adequate time for individuals to read the draft before an in-person meeting.
 - Encourage community partners to contact the person(s) who drafted the manuscript or the community liaison if questions arise as they read the draft.
 - Decide as a group whether authors should send their feedback to the full group or to the first author(s).
 - The manuscript is discussed at an in-person meeting with all authors.
 - Meeting in person is critical to everyone's voice being heard.
 - The first author(s) incorporates the discussion and feedback into the manuscript and re-sends it to all authors. The authors again provide feedback and edits.
 - The process is repeated until everyone feels the manuscript is complete.

Travel and conference arrangements

- Include funds in project budgets to support community partners' attendance at state, regional and/or national conferences so they can participate in presenting the project's research findings.
 - Community members may not have the financial resources to pay for conference expenses and then wait for reimbursement.
 - It is helpful if the project can pay as much as possible up front, such as conference registration, airline/train tickets and hotel.
- Describe both verbally (via telephone or in-person meeting) and in writing (email and/or hand-out) all travel details, such as:
 - Conference registration fee – who will pay this.
 - Transportation – provide any options and be clear about which ones/amounts will be reimbursed, who will book air or train travel, mileage reimbursement for automobile travel, and reimbursement for airport parking.
 - Hotel – who will make lodging reservations.
 - Food/per diem – who will pay for this and if receipts will be required; remember most people are not accustomed to keeping receipts or getting itemized receipts.
 - Be clear about what expenses will be reimbursed and any limits on reimbursement amounts.
- Have one person on the project team serve as the “travel coordinator.”
 - This person can organize everyone's conference registration, air and ground transportation, hotel, and travel reimbursement.
 - If another entity is supporting a community member's travel (such as through a travel scholarship), the travel coordinator may need to serve as a liaison between both parties, staying on top of all deadlines.
 - Keep a file with each person's date of birth, how their name is spelled on their photo ID, frequent flier numbers and preferred seating so this information is in hand each time travel is booked.
 - Create a list with each person's arrival and departure time, mode of transportation/flight, and cell phone number; find a way to communicate with everyone throughout travel days to assist with transitions.
 - Provide a handout that includes conference information such as a map that includes lodging and meeting addresses, and everyone's cell phone numbers so they can contact each other and the travel coordinator if they have questions.
 - If community partners are driving and the location is not straightforward (such as on campus) someone may need to be available to find drivers and lead them in.
 - Consider arranging for group lunches and/or dinners so everyone can share what they are learning.
 - If itemized receipts are required for reimbursement, the travel coordinator can give everyone an itemized checklist of the receipts they need to save in a manila envelope to take in their luggage.

- Have a backup of the team’s presentation slides and posters on a thumb drive in case they are left at home by mistake.

Attending a conference

- It can be overwhelming for community partners to attend professional conferences.
- It is helpful for researchers/agency/organization staff to “host” their community partners at conferences.
 - Ensure everyone knows how to get to the venue.
 - Meet to check in for registration.
 - If the conference has multiple concurrent sessions, decide who will attend which sessions; consider attending sessions together and/or schedule times/locations to meet during the day to check in.
 - Have meals together.
 - Introduce community partners to others.
- Plan to visit the exhibit hall. Picking up free items from booths is often a new experience for community partners and enables them to bring back gifts for their families.

Growth throughout a funded project

Both researchers/agency/organization staff and community partners will grow throughout a partnership; e.g.,

- Community partners may gain the knowledge and skills of researchers/agency/organization staff; e.g.,
 - How to ask research questions.
 - What questions to ask of other researchers/agencies/organizations who want to partner with them.
 - How to plan research or other projects.
 - How to develop research/project instruments, such as surveys and questionnaires.
 - Gain knowledge of “human subjects” research protections, the role of the IRB, and IRB applications; become CITI and HIPAA trained.
 - How to lead focus groups.
 - How to analyze data, both qualitative and quantitative.
 - How to write abstracts and manuscripts and how to prepare posters.
 - How to present posters and give oral presentations at conferences.
- Researchers/agency/organization staff may gain the knowledge and skills of community partners; e.g.,
 - Understand a community’s strengths, interests and needs.
 - Identify research/project approaches that are acceptable to and will work in a community.
 - Recognize that hearing and sharing stories is a valid way of communicating.

- Everyone becomes more aware of and sensitive to the strengths and needs of each individual and organization in the partnership.

Recommendations from Community-Engaged Researchers

- If you have access to a Community Liaison, meet with them to understand how they can support you and your research; a Community Liaison is invaluable.
 - If you are at an institution with a NIH Clinical and Translational Science Award (CTSA), the community engagement “core” or similar group may provide Community Liaison services.
 - If you seek to hire a Community Liaison, useful experience, skills and qualities include: broad connections in the partner community(s), excellent facilitation skills for both small and large group meetings (includes good listening skills and an ability to be tactful), and some understanding of the research process (does not need to have extensive research experience).
- Reconnect with the community partner once a project is funded.
 - Remind them about the project and the project details.
 - Re-discuss roles and expectations. Recognize that changes may have taken place in an organization and/or in people’s lives since the grant proposal was written.
 - Re-discuss the budget.
 - Was the requested budget funded? If not, discuss as a team where to make budget cuts.
 - Discuss how funds will be distributed.
- Community partners may need technical assistance to carry out their part of a project; this may not emerge until partway into a project; e.g.,
 - Community organizations may need technical assistance to financially manage a subcontract or to supervise community members they hire.
- Be willing to be flexible and adapt as needed to achieve the project goals.
- Recognize that community partners often have solutions to challenges that arise.
- Check in frequently with community partners and hold monthly or quarterly partnership meetings to formally discuss the project’s progress.
- Technology
 - Discuss and identify technologies that work for everyone.
 - Discuss any research requirements for data to be recorded in a secure, HIPAA-compliant database (e.g., REDCap); community partners may need training in using the database, as well as the means to access it, such as a laptop and internet connection.
- Share with community partners ways in which the collaboration has enhanced your approach to research, practice or other work and/or your life.

Ways to Proceed if a Project is Not Funded

Recommendations from Community Leaders

- Keep in touch.
 - Check in, email, go to lunch.
 - Give a short presentation at a community meeting or event.
 - Share other funding opportunities for collaborative projects or funding opportunities community partners can apply for themselves.
 - Help community partners network and make connections that may be beneficial for their community.

Recommendations from Community-Engaged Researchers

- Discuss together how the relationship may change. What do we do next?
- Look for additional opportunities – either other funding sources or smaller amounts of funding that could get the project started while resubmitting the original grant proposal.

Disengaging from a Community When a Project Ends

Recommendations from Community Leaders

- Hold a debriefing at the end of the project; discuss where the partnership could go from here.
- Discuss whether there are community organizations or members who can continue to carry out aspects of the project.
- Help take the work to the next level of impacting policy.

Recommendations from Community-Engaged Researchers

- Meet with community partners at the end of a project; discuss if there are additional opportunities to work together.

Appendix A: 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 B: Example of a 2-page Project Summary 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 C: Example of a Detailed Project Summary and Budget for Community Partners

Project: HPV Vaccine Community Focus Groups with Parents of Children ages 11-17

PI: Deanna Kepka, PhD, MPH, University of Utah

Funders: Primary Children's Hospital Foundation and an award from the National Center for Advancing Translational Sciences from the National Institutes of Health under Award Number KL2TR001065



Huntsman Cancer Institute and University of Utah
**Collaborative Community Based Research Proposal:
HPV Vaccine Community Focus Groups with Parents of Children ages 11-17**

Deanna Kepka, PhD, MPH
Assistant Professor
College of Nursing, University of Utah
deanna.kepka@hci.utah.edu
Office: 801.587.4565 | Cell: 206.321.0936

Background

This collaborative community based research proposal seeks to initiate a university-community partnership among the members of Community Faces of Utah (CFU), the Huntsman Cancer Institute, and the University of Utah. Currently, a vaccine exists to prevent the majority of cervical cancer in women and other human papillomavirus (HPV) related cancers among men and women.¹ Although widespread use of the vaccine will significantly lower the burden of HPV-related cancers, uptake is far below national goals. In Utah, very few adolescents have initiated receipt of the vaccine and completed the vaccination series.² We want to learn why this is happening and what we can do to improve it. We especially want to ensure that diverse and vulnerable populations receive culturally and linguistically appropriate services and educational materials about the HPV vaccine.³⁻⁷ We also aim to improve access for these populations.

In the United States, more than half of sexually-active men and women are infected with genital HPV at some point during life.^{1,8-10} It is the most common sexually transmitted virus. Annually, about 6 million new cases of HPV emerge nationally.^{1,8-10} Approximately 20 million people are currently infected nationwide.^{1,10} The majority of HPV infections are asymptomatic, and it is possible for the body to eradicate the infection on its own.^{1,10} The major concern, however, centers on HPV as a known cause of cervical cancer—the 2nd leading cause of cancer deaths among women worldwide.^{1,10} In the United States, an estimated 12,000 women will get cervical cancer this year, and an estimated 4,000 will die from it.^{1,10} Less common cancers (vaginal and vulvar cancers for women, and anal and oropharyngeal cancers for both men and women), as well as genital warts, are also attributable to HPV.^{1,10} While no known cure for HPV infections exists, some treatments do exist for some complications from the virus.^{9,10}

There are two forms of vaccine that can be given to prevent HPV, a bivalent (HPV2) form and a quadrivalent form (HPV4).^{1,8,10} The more common of the two, known by the trade name Gardasil®, protects against four known cancer-generating HPV subtypes (6, 11, 16 and 18).^{1,8,10,11} The Centers for Disease Control and Prevention recommend a three-dose series of Gardasil® for both males and females to prevent cancers and the transmission of the virus.^{1,8-10,12,13} When given before exposure to the virus, this vaccine prevents most cases of cervical cancer in females.^{1,9-11}

The FDA approved the use of the quadrivalent vaccine in girls ages 9 to 26 years to prevent cervical cancer and other complications six years ago.^{1,11} The vaccine was introduced as a routine part of health care for females to prevent cervical cancer and other diseases caused by HPV.^{1,11} Subsequently, recommendations for receipt of the quadrivalent vaccine expanded to include males aged 9 to 21 years to reduce the prevalence, transmission and complications from HPV.⁸ Vaccine efficacy is highest when given prior to exposure to HPV.^{1,8-14}

The Healthy People 2020 objective for HPV vaccination series completion among females is 80% yet more than six years after HPV vaccine approval, only 33% of U.S. females and 7% of males ages 13-17 years have completed the series. Possible explanations for the low number of HPV immunized people include lack of parental knowledge about HPV and the HPV vaccine, lack of health care provider recommendations for the vaccine, missed opportunities for vaccination, religious and cultural factors, and beliefs that vaccinating early adolescents against a STI is unnecessary and/or may promote sexual activity.

Understanding factors related to HPV vaccination initiation and completion of the 3-dose series is key to identifying intervention targets for initiation and completion of the HPV vaccine. In Utah, uptake of the first dose is **below the national average among adolescent females** and **completion of the 3-dose series is among the lowest in the nation.** Furthermore, uptake of the HPV vaccine is especially critical for vulnerable populations because cervical cancer disproportionately impacts certain demographic groups. For example, Latinas have the highest incidence of cervical cancer and are the most rapidly growing minority population in many states, including Utah. Reasons for the alarmingly low HPV vaccination rates in Utah are largely unknown.

Objectives

The purpose of this proposal is to explore awareness, knowledge, and interest in HPV vaccination among some of Utah's minority and underserved populations. We propose holding mini-surveys and focus groups at a number of diverse community locations. These locations will be determined by each community-member group associated with CFU:

- Best of Africa (African immigrant community)
- Calvary Baptist Church (African-American community)
- Hispanic Health Care Task Force (Hispanic-Latina/o community)
- National Tongan American Society (Polynesian community)
- Urban Indian Center of Salt Lake (Native-American community)

We anticipate conducting two focus groups with each community group, totaling 10 group sessions. We hope to conduct these focus groups between February and July of 2014 at locations chosen by each of the community groups.

In this context, a focus group is a moderated discussion among a small group of individuals who collectively represent their respective community. For example, parents are responsible for accessing health care for their children. To better understand why adolescents in Utah are not receiving recommended HPV vaccinations, we need to understand parents' awareness of the vaccine, its recommendations, and other associated factors. **These group discussions will target parents of adolescent girls and boys 11 to 17 years-old.**

At the beginning of each session, a script describing the meeting's purpose and use of the information shared will be read and permission to record the discussion will be solicited. We anticipate that each focus group will last between 60 and 90 minutes and will include 8-12 parents.

Data Collection and Data Use

We accept and are committed to protections for study participants, including a comprehensive and fully-informed consent process. A sample list of questions to be included in the focus group discussions is given below for your review. This list is non-exhaustive, and serves to simply give a general idea of intended content and how questions may be presented to the groups.

Sample Question List for Focus Groups

1. Have you ever heard of cervical cancer? If yes, what are some tools used to prevent and detect cervical cancer?
2. Have you ever heard of the Human Papillomavirus? (You may have also heard this called HPV) If yes, please tell me what you know about HPV...
3. Have you ever heard of the HPV vaccine?
If yes, please tell me what you know about the HPV vaccine.
4. Has a doctor or other health professional ever recommend the HPV vaccine for your child/children? If yes, has your child/children received any of the doses required in the HPV vaccination series? If no, if a doctor or other health professional recommended the HPV vaccination for your child/children, what would be your response?
5. How many times has a doctor or other health professional ever recommended the HPV vaccine for your child/children?
6. How likely are you to receive the vaccine for your daughter in the next 12 months?

Additionally, we would like to include a mini survey prior to each focus group that will explore demographic factors related to cervical cancer, adolescent vaccination, and cancer prevention. The mini surveys themselves will be adapted for participants with the guidance of each demographic group. This will allow us to understand differences among the respondents. Responses to these mini surveys will subsequently facilitate tailoring each group session both culturally and linguistically for the target audience. A sample list of potential questions for the mini survey follows.

Sample Question List for Mini Surveys

1. Would you please tell me how old you are? [If the respondent resists, read the categories below and ask them to tell you into which category they fall]:
18-25
26-30
31-35
36-40
41-50
51-60
60+
2. What is your occupation?

3. How many daughters between ages 9-14 live in your household?
4. Please describe your race or ethnicity.
5. Where were you born? If not in the United States, how many years have you lived in the United States?
6. Where were your parents born?
7. What languages do you speak?
8. What languages do you speak at home?
9. What languages do you speak with your friends?
10. How many years of education have you had? [It is okay to note through 8th grade, high school, etc.]
11. Into which category does your total household income for one year fall?

Focus groups can be conducted at a location chosen by each community group. Tailoring recruitment efforts, location and content for each demographic group serves to maximize effectiveness of the sessions. Providing an environment where participants feel comfortable being approached to share personal opinions increases willingness for mutual communication and understanding.

Information obtained from the focus group discussions will inform the development of culturally and linguistically appropriate strategies that will more effectively address the vaccination gap for adolescents in Utah. As more-strategic health interventions are implemented with the use of the data from these survey sessions, we anticipate an increase in awareness and vaccine uptake among diverse populations.

Summary

We believe that this effort will support and sustain the mission and vision of CFU. It is written in the motto of CFU that, "Together we achieve more." This collaborative research effort seeks to build upon and utilize the established community collaboration among CFU member groups and institutions. Additionally, this research collaboration supports the written vision statement of CFU.

Our purpose in engaging this discussion is to enhance existing knowledge regarding what affects initiation of HPV vaccine coverage among adolescents in Utah. Exploring demographic factors will reveal what influences the cervical cancer burden, adolescent vaccination, and cancer prevention in Utah and nationally.

Budget

In reference to feasibility and financial considerations, we are prepared to pay costs associated with incentives for study participants, recruitment of focus-group participants, facility use and facilitator fees. Each session will be led by two facilitators: one from our research group and one from the community group of interest. The community-based facilitator will be compensated for their time. Additionally, we suggest a \$25 gift card to Wal-Mart as an incentive for participants to compensate them for their time and willingness to share their viewpoints.

Item	Cost	Estimate
<u>Facilitator from each of 5 community groups:</u> -Best of Africa (African immigrant community) -Calvary Baptist Church (African-American community) -Hispanic Health Care Task Force (Hispanic-Latina/o community) -National Tongan American Society (Polynesian community) -Urban Indian Center of Salt Lake (Native-American community)	\$ 150 per session * 10 sessions	\$ 1,500
Use of facilities	\$ 500 per session * 10 sessions	\$ 5,000
Recruitment	\$ 500 per session * 10 sessions	\$ 5,000
Participant Incentives (8-12 participants per session)	\$ 25 per participant * 120	\$ 3,000
Total Estimated Reimbursement to CFU from Huntsman Cancer Institute		\$ 14,500

References

1. Markowitz LE, Dunne EF, Saraiya M, Lawson HW, Chesson H, Unger ER. Quadrivalent Human Papillomavirus Vaccine: Recommendations of the Advisory Committee on Immunization Practices (ACIP). *MMWR. Recommendations and reports : Morbidity and mortality weekly report. Recommendations and reports / Centers for Disease Control.* Mar 23 2007;56(RR-2):1-24.
2. Centers for Disease Control and Prevention. Teen Vaccination Coverage. [Dataset]. 2011; Available at http://www2a.cdc.gov/nip/coverage/nisteen/CountNIS-TEEN.asp?fmt=v&rpt=tab01_iap_2011.xlsx&qtr=Q1/2011-Q4/2011. Accessed December 31, 2013.
3. National Standards for Culturally and Linguistically Appropriate Services in Health Care. Washington, D.C.: Department of Health and Human Services, Office of Minority Health; 2001:47-111.
4. New standards address patient communications. *Healthcare benchmarks and quality improvement.* Jul 2011;18(7):81-82.
5. Cheng EM, Chen A, Cunningham W. Primary language and receipt of recommended health care among Hispanics in the United States. *Journal of general internal medicine.* Nov 2007;22 Suppl 2:283-288.
6. Kuo DZ, O'Connor KG, Flores G, Minkovitz CS. Pediatricians' use of language services for families with limited English proficiency. *Pediatrics.* Apr 2007;119(4):e920-927.
7. Leyva M, Sharif I, Ozuah PO. Health literacy among Spanish-speaking Latino parents with limited English proficiency. *Ambulatory pediatrics : the official journal of the Ambulatory Pediatric Association.* Jan-Feb 2005;5(1):56-59.
8. FDA licensure of quadrivalent human papillomavirus vaccine (HPV4, Gardasil) for use in males and guidance from the Advisory Committee on Immunization Practices (ACIP). *MMWR. Morbidity and mortality weekly report.* May 28 2010;59(20):630-632.
9. Centers for Disease Control and Prevention. HPV Vaccine Safety. [web page]. 2013; Available at <http://www.cdc.gov/vaccinesafety/vaccines/HPV/Index.html#resources>. Accessed December 25, 2013.
10. Centers for Disease Control and Prevention. Vaccine Information Statement (Interim): HPV Vaccine (Gardasil). [web page]. 2012; Available at <http://www.cdc.gov/vaccines/hcp/vis/vis-statements/hpv-gardasil.html>. Accessed December 25, 2013.
11. Kepka D, Coronado G, Rodriguez H, Thompson B. Acculturation and HPV infection among Latinas in the United States. *Prev Med.* Aug 2010;51(2):182-184.
12. Food and Drug Administration. Product approval-prescribing information [package insert]. Gardasil [human papillomavirus quadrivalent (types 6, 11, 16, and 18) vaccine, recombinant]. *Merck & Co, Inc: Food and Drug Administration* 2009; Available at <http://www.fda.gov/BiologicsBloodVaccines/Vaccines/ApprovedProducts/UCM094042>. Accessed 12/25/2013.
13. Food and Drug Administration. Gardasil Vaccine Safety: Information from FDA and CDC on the Safety of Gardasil Vaccine. [web page]. 2009; Available at <http://www.fda.gov/BiologicsBloodVaccines/SafetyAvailability/VaccineSafety/ucm179549.htm>. Accessed December 25, 2013.
14. Food and Drug Administration. Approved Products: Guardasil. [web page]. 2013; Available at <http://www.fda.gov/biologicsbloodvaccines/vaccines/approvedproducts/ucm094042.htm>. Accessed December 25, 2013.

Appendix D: Research Project Planning Guide

The Research Project Planning Guide was developed as a tool to facilitate discussions between researchers/agency/organization staff and community partners as they collaboratively plan a project. We suggest that each partner (researcher and community) complete sections of the Planning Guide before meeting to discuss ways they can reach shared goals and plans.

Research Project Planning Guide

1. Project Title or Topic				
2. Project Collaborators: What are the best ways to communicate?				
Name	Phone	Email	Preferred way(s) to communicate	Best days, times, & locations to meet
3. Project Funder or Potential Funder				
Agency/Organization providing the funding				
Grant announcement name, number & web link				
Proposal due date				
Maximum number of years for project				
Budget Guidelines				
Specific topics of interest in the grant announcement				
4. What are the overall goals of this project?				
Community		Researchers		Shared
5. What strengths does each partner bring to this project?				
Community		Researchers		Shared

6. What resources does each partner bring to this project?		
Community	Researchers	Shared
7. In what ways can this project be a “win” for each partner? <i>In what ways can this project build community capacity?</i>		
Community	Researchers	Shared
8. What is the research design (plan) for this project?		
9. What type(s) of data will be collected?		
10. <i>If applicable:</i> How will the research instruments (surveys, focus group/interview guides, etc.) be developed?		
Community	Researchers	Shared
11. Who will be eligible to participate in this research?		

Who will not be eligible to participate?		
12. How will research participants be recruited? How many will need to be recruited?		
13. Who will be responsible for submitting the application to conduct “human subjects” research to the Institutional Review Board?		
Who will need to have “human subjects” training and certification?		
Community	Researchers	
14. How and where will the project data be stored?		
Community	Researchers	Shared
15. Who will participate in analyzing the project data?		
Community	Researchers	Shared
16. 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>		
Community	Researchers	Shared

17. Project Personnel:*What tasks are needed to carry out the project? Who will do these tasks?**What training (if any) will people need to do the work? How much time will be required to do the work?*

Task/Role	Community	Researchers	Training	Time

18. What will it cost to carry out this project? (calculate the budget on a spreadsheet, keeping the following in mind)

	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 & Administration (overhead) rate		

19. In what ways will the project's findings or outcomes be shared with others?

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?	

20. What is the timeline for this project?

Month or Quarter	Tasks	Person responsible for leading task

21. In what ways might this project be sustainable beyond the grant funding period?		
Community	Researchers	Shared
22. What are the expectations for collaboration/interaction beyond the end of this project?		
Community	Researchers	Shared
23. What will we do if this grant proposal is not funded?		
Community	Researchers	Shared

Appendix E: Example of Progress Report

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

QUARTERLY PROGRESS REPORT

CHC-UWAG Phase II

Coalition for a Healthier Community - Utah Women and Girls

GRANT #: 1 CCEWH111018-01-00
Federal Funding Agency: Dept Health and Human Services – Office on Women’s Health
Locally Administered by: University of Utah – Center of Excellence in Women’s Health
Total Project Period: Sept. 1, 2011 – Aug. 31, 2016

CFU Organization: _____

Quarterly Report for Period: Dec. 1, 2012 – Feb. 28, 2013

BUDGET TRACKING:

Payment Schedule (\$4,500 each quarter):

Year	Q1		Q2		Q3		Q4	
1	Sept 1 – Nov 30, 2011	X	Dec 1 – Feb 29, 2012	X	Mar 1 – May 31, 2012	X	Jun 1 – Aug 31, 2012	X
2	Sept 1 – Nov 30, 2012	X	Dec 1 – Feb 28, 2013		Mar 1 – May 31, 2013		Jun 1 – Aug 31, 2013	
3	Sept 1 – Nov 30, 2013		Dec 1 – Feb 28, 2014		Mar 1 – May 31, 2014		Jun 1 – Aug 31, 2014	
4	Sept 1 – Nov 30, 2014		Dec 1 – Feb 28, 2015		Mar 1 – May 31, 2015		Jun 1 – Aug 31, 2015	
5	Sept 1 – Nov 30, 2015		Dec 1 – Feb 29, 2016		Mar 1 – May 31, 2016		Jun 1 – Aug 31, 2016	
Total Received to date:			Total Spent:			Balance in UWAG Account:		

ANNUAL BUDGET GUIDELINES

Community Wellness Coach Wage: ¼ time @ \$17/hr. for 10 hours per week	\$8,000
Allowance: For travel, childcare, miscellaneous expenses:	\$1,000

Cash for Data Collection: \$20 at 1, 4 and 8 month follow-ups and \$40 at 12 months for 24 participants (12 active intervention/12 control) (Total 24 participants at \$100 each)	\$2,400
Athletic Bra: (or other incentive) for each participant (24 x \$25 each)	\$600
Course Incentives: New Leaf Participants: Food and health tools to support meeting goals (12 people at each of 12 meetings - \$12.50 per person per meeting)	\$1,800
Health Fair costs	\$500
CFU Leader: (\$1000) /organization fiscal expenses (10%)	\$2,800
Balance: Wellness Coach training, evaluation - miscellaneous	\$900
TOTAL	\$18,000

Expenditure for this quarter only:

Expenses	Amount projected \$	Actual spent \$	comments
CWC wages			
Leader expenses			
Other expenses (itemize)			
List other expenses			

COMMUNITY LEADERS:

Meetings Attended:

	Month 1	Y/N	Month 2	Y/N	Month 3	Y/N
UWAG Advisory Board	Dec. 17, 2012		Jan. 28, 2013		Feb. 25, 2013	
CFU Meeting	Dec. 3, 2012		Jan. 14, 2012		Feb. 22, 2012 (CFU Retreat)	
Event Planning						
Meetings with CWC						
Time spent at other meetings (as listed on Outreach Tracking Document)						

Time spent doing other UWAG business			
Total # of people reached at other meetings (as listed on Outreach Tracking Document)			

COMMUNITY WELLNESS COACHES (CWCs):

IMPORTANT! – Time sheets are to be collected and copies given to Leanne.

Monthly summaries to be reviewed with leader and submitted to Leanne
(These will be used for the economic analysis of the project.)

Meetings Attended:

	Month 1	Y/N	Month 2	Y/N	Month 3	Y/N
Monthly meeting with College of Health						Y
Meetings with Community Leader						
Training						
Event Planning						
Others– please list						
Total hours spent at meetings						

List monthly group activities for New Leaf participants:

Date	Activity	Location	Number in attendance
1.			
2.			
3.			

Total Hours Worked by CWC (from timesheets)	Q1	Q2	Q3	Q4

STUDY INFORMATION:

This quarter only				TOTAL number of participants to date
New recruits (contact information obtained)	Consented participants	Number who completed baseline	Number who discontinued	
Outreach— (estimate number of women and girls touched by our interventions, education)				

COMMENTS:

What was successful for this quarter?

CWC:

Community:

UWAG/CFU:

What can be improved for this quarter?

CWC:

Community:

UWAG/CFU:

Goal for next quarter:

CWC Goal:

Community Goal:

UWAG/CFU Goal:

UWAG/CFU team will assist community in goals by...

Submitted by:

CFU Leader

Date

Received by:

UWAG Representative

Date

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 2 or 3. **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:

This study was supported by a grant from the Office on Women's Health, Department of Health and Human Services Grant number: 1CCEWH111018-01-00. Valentine Mukundente, O. Fahina Tavake- Pasi, Eru Napia made important comments on an earlier draft of this manuscript. The

authors would also like to acknowledge all the coaches that collected data for this study, and the public health students who have assisted in the project. The authors also would like to especially acknowledge the contributions from the Coalition for a Healthier Community for Utah Women and Girls.

Members include:

- Utah Women’s Health Coalition
- 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
- University of Utah Center of Excellence in Women’s Health: Leanne Johnston, Sara E. Simonsen, Kathleen B. Digre
- University of Utah, College of Health: Patricia Eisenman
- 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.

Appendix G: Example 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

Data Ownership and Use Agreement

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 H: Other Resources

Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee Task Force on the Principles of Community Engagement. Principles of Community Engagement, Second Edition.

https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

The Examining Community-Institutional Partnerships for Prevention Research Group. *Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill-Building Curriculum*. 2006. <http://depts.washington.edu/ccph/cbpr/index.php>

Newman SD, Andrews JO, Magwood GS, Jenkins C, Cox MJ, Williamson DC. Community advisory boards in community-based participatory research: a synthesis of best processes. *Prev Chronic Dis* 2011;8(3). <https://blogs.cdc.gov/pcd/2011/04/08/community-advisory-boards-in-community-based-participatory-research-a-synthesis-of-best-processes/>. Accessed January 29, 2018.

Kelly G, Wang S-Y, Lucas G, Fraenkel L, Gross CP. Facilitating meaningful engagement on community advisory committees in patient-centered outcome research. *Prog Community Health Partnership*. 2017;11(3):243-251. Available (free) at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5679445/>.