

ORGANIZATION NAME: Regents of the University of California on behalf of the Riverside campus
 PROJECT NAME: Gathering of Good Minds: Engaging Native Americans in Wellness
 PROJECT LEAD: Juliet McMullin

PROJECT WORKPLAN AND TIMELINE

Insert additional rows and use continuation pages as needed. Limit 21 pages total, excluding the Protection of Human Subjects, Subcontracts, and References Cited sections. See PCORI Engagement Awards Application Guidelines for additional help.

A. Workplan (Limit 15 pages)

Background. This application addresses multiple problems associated with the collaborative engagement of researchers, clinicians, and community members to address chronic illness and well-being for our local Native American communities.

Problem One: Chronic illnesses (e.g. diabetes, high blood pressure, and heart disease) within a context of historical trauma are serious, highly prevalent health issues facing Native American populations, including the 12 tribes in the inland Southern California area. A few programs have been shown to be effective in assisting Native American populations to address these various health issues, but they are not widely used nor have they been tested for comparative effectiveness.

Problem Two: From the perspective of researchers, engaging Native American communities in comparative effectiveness research can be challenging. A foundation of trust, requiring considerable time and effort, must be built prior to initiating research.

Problem Three: Researchers and clinicians are often unaware of the impact of historical trauma on Native American health and well-being. Additionally, many do not understand Native American culture or points of view regarding health in general and chronic illnesses in particular. In order to engage in culturally appropriate comparative effectiveness research researchers and clinicians need to be better informed.

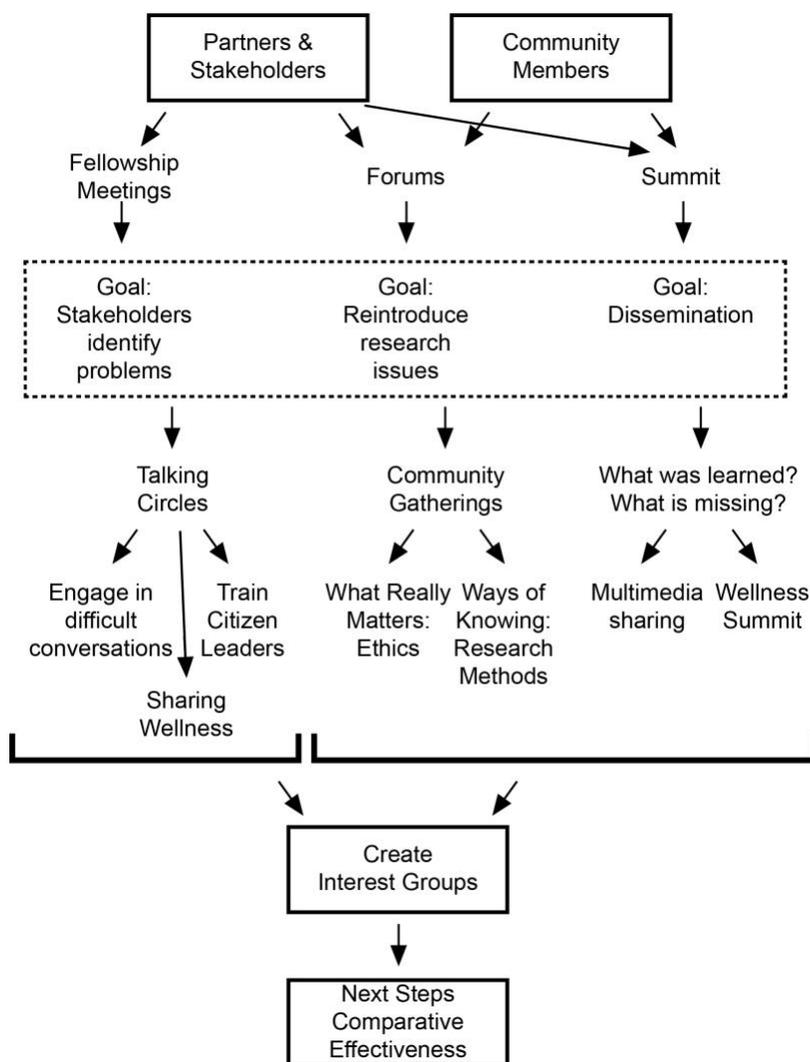
Problem Four: Clinician providers and administrators at the Riverside/San Bernardino County Indian Health Inc. (RSBCIHI), especially Dr. Kendall Shumway who leads the diabetes program, would like to partner with researchers in comparative effectiveness research but are not well-versed in its methodologies. A better understanding of comparative research methods would allow providers to be full partners in devising research.

Proposed Solutions. This project is based in a commitment to engaging patient communities and providers as equal partners in research, and developing a program of co-learning so all stakeholders understand how their knowledge and practices guide effective and sustainable solutions to health issues affecting Native American patients. Using a modified version of the Citizen Health Care Model (1), we will build trust among stakeholders by listening to and creating opportunities for patients and other stakeholders to be equal partners. Our project will increase local capacity for partnered research between Native American patients and supporting family and friends, providers, RSBCIHI, UCR faculty, and medical and graduate students. The five components of the proposed project are: 1) create a Gathering of Good Minds project Action Planning Committee (APC), chaired by representatives from our four stakeholder groups; Kendall Shumway (RSBCIHI provider project lead), Juliet McMullin (UCR researcher and project lead), Luella Thornton (Patient community project lead), and Sherri Salgado (RSBCIHI board project lead), and consisting of additional patient community members (with experience with chronic illness), health providers, faculty, and

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RSBCIHI Board members to oversee, guide, and provide key input into all aspects of the project; 2) hold two

“Gathering of Good Minds” Project Plan



consecutive series of Fellowship meetings (co-learning events) where all stakeholder groups are invited to learn about patient community and researcher knowledge and practices around various chronic illnesses such as diabetes, cancer, high blood pressure, overall well-being and historical trauma; 3) train Citizen Leaders to have expertise in working with researchers and health service providers in our local Native American community; 4) enhance specific knowledge and training around comparative effectiveness research (CER) by running two community forums that focus on ethics and research, and methods associated with CER; and 5) regular multimedia dissemination of issues raised and discussed in the Fellowship meetings to engage the broader Native American community who cannot attend the Fellowship meetings and to build a foundation of trust. As an additional step in this dissemination, we will plan a Wellness Summit wherein each stakeholder group will share lessons learned and discuss potential future research collaborations.

Longstanding Interest in Native American Health. The University of California, Riverside sits on the ancestral lands of the Cauhilla. It is also home to the California Center for Native Nations and the Rupert Costo Endowed Chair for Native American Indian Affairs. A primary interest for the endowment is to engage scholars in

oral histories and learning about Native American communities, culture, music, dance, art and storytelling rather than reliance on documents. UCR is home to a strong Native American Student Association, which has hosted the Annual Medicine Ways conference for over 34 years. This conference brings community members, tribal elders, healers, and Native scholars to share knowledge about Native medicine and socio-historical contexts of health and healing for Native Americans. Dr. Juliet McMullin, a cultural and medical anthropologist (proposed PI of this application) and Dr. Cliff Trafzer (professor, UCR Department of History, Rupert Costo Endowed Chair and Native American from the Wyandot tribe of Ohio) have built relationships with several of the 12 local Native American tribes over many years. Leaders from the local tribes have earned graduate degrees from UCR, with Dr. Trafzer as their primary MA or PhD advisor. Five years ago

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Dr. McMullin met Dr. Kendall Shumway, director of the Diabetes program at Riverside-San Bernardino County Indian Health Inc. (RSBCIHI), and worked with him to design and write an unfunded application related to Native gardens and diabetes. Besides this effort and the on-going conversations between Dr. McMullin, Dr. Shumway, and Dr. Trafzer there have been little to no attempts to bring to life an active partnership that could involve researchers, health providers, and the Native American patient communities they serve. The formation of the Center for Healthy Communities at the UC Riverside School of Medicine provides the infrastructure, support, and additional expertise needed to allow a formal building of this important partnership. In recognition of our efforts at collaboration, Mr. Ernest Siva, respected elder from the Morongo Band of Cahuilla Mission Indians, gave us a name for our project: *Chihuwm Piiuywmk Inach*, a Serrano phrase that translates to *The Gathering of Good Minds*. This represents the broad goals of the proposed project, which are aimed at building a community/university/health services research network to effectively engage in patient-centered research.

Center for Healthy Communities. The University of California, Riverside (UCR) educates more than 19,000 undergraduate and about 2,500 graduate students each year. UCR consistently excels on rankings related to ethnic diversity, social mobility of students, and responsiveness to community needs (2-4). The environment of UCR is one in which diversity is highly valued as a cornerstone for both education and research. In 2013, UCR initiated a new community-based School of Medicine (SOM), the first public medical school west of the Mississippi in 50 years. The SOM is innovative in several respects, including its approach to admissions (which are designed to enroll and train more doctors from racial and ethnic backgrounds that are under-represented in medicine) and its approach to medical education (which emphasizes community-based primary care, as well as training in prevention, public health, chronic disease management, and cultural competence). Students begin their clinical experience during their second week of training, giving them time to develop on the ground relationships with local physicians and patients. This long term relationship also sets the groundwork for practice improvement projects based on questions students develop in partnership with their preceptors and patients and that meet the needs of that location. The inland Southern California area, which is the general service area of the new medical school, is the fourteenth largest and has the highest poverty rate of any metropolitan areas in the U.S. (5) Its population is highly diverse and shows health disparities following historical inequalities. The population in this area has a relatively high percentage of Native American residents (~1.9%). With twelve resident tribes, Riverside-San Bernardino county has the second largest number of federally recognized tribal governments.

In 2013, the SOM leadership made a strategic decision to begin building a research center that focuses on community-based and population health research. The leadership considers this proposed type of research as central to the SOM mission. In 2014, Greer Sullivan, MD, MSPH, was recruited to develop and lead the new Center for Healthy Communities (CHC). The CHC mission statement, crafted by community stakeholders during two retreats, reads, *“The CHC will lead and facilitate innovative research to improve the health of the culturally, linguistically, and economically diverse communities in the region, especially those that are medically underresourced. Our goal is to build collaborations between researchers and communities through education and research that addresses our communities’ needs and promotes health equity.”* Among the first faculty that Dr. Sullivan engaged was Dr. McMullin, in large part because of her longstanding interest and experience in working with several different indigenous populations. Dr. McMullin then brought Drs. Trafzer and Shumway to the table to begin a discussion as to how to best move forward a partnered and patient-centered research agenda.

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Riverside-San Bernardino County Indian Health Inc. Established in 1968 and incorporated in 1974, RSBCIHI is a consortium of 9 of 12 federally recognized tribes in Riverside and San Bernardino Counties. RSBCIHI's mission is to provide culturally sensitive healthcare, respect the traditional customs of Indian Communities, and promote wellness and early intervention to achieve healthy lifestyles. RSBCIHI operates seven ambulatory and behavioral health clinics throughout its two-county service area, including the two proposed sites for the engagement activities: San Manuel Indian Health (6,750 active users) and the Morongo Indian Health (8,197 active users) clinics.

RSBCIHI is the largest Indian Health care system in the state of California and provides an extensive array of services: Medical (e.g., Primary Care, Pediatrics, Women's Health, Pain Management, Podiatry, and Wound Care), Dental, Optical, Laboratory, Pharmacy, and Radiology as well as an Outreach Program with Public Health Nurses and Community Health Representatives. It is a 501c3 non-profit and is governed by a board consisting of two elected representatives from each of the nine Tribes. Mr. Jess Montoya, CEO oversees the day-to-day operations of the corporation, while Dr. Karen Davis, MD, Clinical Director oversees seven clinics. Eligible patients are from the local tribes, but Native Americans from across the country and also non-Native spouses and immediate family members seek care at RSBCIHI clinics. RSBCIHI is a Federally Qualified Health Center and receives income through third party billing as well as directly from the Indian Health Service.

Preparing the application. The preparation of this application has been facilitated by a series of meetings wherein dynamic conversations led to the development of core goals and topics for our proposal. In October 2014, Drs. Shumway and Davis met with Drs. McMullin and Sullivan, and Ms. Reaves to discuss the possibility of developing a study to test a family-based care model for diabetes management. During the development of the concept paper, we carefully reviewed the literature and were introduced to the Citizen Health Care Model (CHCM) as a community engagement method for collaborating "with" patients and family members to "increase ownership" of a problem (1). This model has been used successfully in projects involving collaboration between academics and Native American groups (6, 7).

For our second meeting we expanded the group of community partners to advise on the development of the project. Led by Dr. McMullin, investigators from the CHC and Dr. Trafzer met with the Diabetes Advisory Board - which consists of individuals representing each of the 9 tribes in the RSBCIHI consortium - and Mr. Montoya, the CEO of RSBCIHI. Our discussion of the concept paper led to the realization that starting with the specific CER proposal, to test a family care model for diabetes management, would be premature. We learned that to begin a conversation in the community with the word "research" would greatly diminish the success of the effort. Following this meeting, we then turned our attention toward collaboratively writing an engagement proposal focused on diabetes. All agreed that an initial step toward research should be building trust and provide training for key stakeholder groups. This approach is congruent with the recommendations of previous researchers who have reported that at least two to three years of involvement with Native American communities are required in order to have an appropriate and effective research collaboration (7, 8). Board members noted repeated requests from patients and their families for more knowledge that would improve patient care. For example, one board member stated she had heard of diabetes but until she saw her relative having to go through multiple treatments she "didn't know it was so severe." With respect to our provider partners Dr. Shumway has noted that while physicians regularly see patients, and they have a desire to engage in research to improve patient outcomes, it is hard for physicians to "think beyond the clinic." From both the patient and provider perspectives there is a need to do more in the areas of patient-

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centered care that is inclusive of critical social relationships from immediate and extended family to barriers to care.

During our follow-up meetings we learned that over the past year Dr. Davis held a series of highly attended talking circles focused on the community describing their health care needs. Many participants indicated to they would like to have more such patient-care oriented events. Dr. Davis and members of the Advisory Board highlighted the patient community's appreciation of the talking circles. Thus, the idea of making the Fellowship meetings a centerpiece of our proposal was well received. The Advisory Board also advised us to address additional topics such as well-being for adults and children, and chronic illnesses. Moreover, the Advisory Board suggested that broadening our engagement focus from diabetes to chronic diseases would result in greater participation from the physicians in the RSBCIHI consortium. Based on these discussions, we decided we would move from a narrow focus on diabetes to a wider focus on patient and provider needs and experiences around chronic illnesses affecting the community and the role of the RSBCIHI system in enhancing wellbeing. The PCORI Engagement Award mechanism is an ideal mechanism to support our efforts at building trust with our research partners and building the capacity of RSBCIHI to engage in CER.

Rationale for Focusing on Native American Well-Being and Chronic Illness

While diabetes is often at the forefront of discussions regarding Native American well-being, leading causes of death nationally and in Riverside County are: 1) heart disease, 2) cancer, and 3) unintentional injuries (9, 10). Equally seldom discussed are the social, historical, political and economic impacts associated with chronic illness prevention, prevalence, and mortality (11, 12). During our conversations with each other and community members, the issues of social, historical, political and economic impacts arose, and were often framed as historical trauma. Our community partner, Luella Vann Thornton, said "...historical trauma is not just a one time event, it is chronic. It affects our well-being." These conversations combined with recent research examining the association between historical trauma and adverse health impacts (13-18), showed us that engaged research will mean not only addressing the physical health of patient populations but also the role of historical and current contexts for that health. A series of conversations with each of our stakeholder groups (see below) have stressed the complex inter-relationships between health issues and patient centered care as intergenerational, and the necessity to 1) attend to the lived experience of the whole family, 2) garner more knowledge about chronic illnesses and their effects on individual and family, and 3) acknowledge and discuss historical contexts as a way to develop effective patient centered research. Previous research with Native American communities also emphasizes the need to incorporate impacts of forced removal from ancestral lands and food, discrimination, denigration of indigenous knowledge systems, and consequent transformation of Native diets to highly processed foods as well as societal restrictions on where and how a Native person can move through public spaces (11-13, 19-21). A PCORI Engagement award will provide time for trust building as well as training for our stakeholder groups in these complicated issues and their relationships to patient centered care and CER. An Engagement award would allow us to collectively prepare to take the next steps toward a collaborative CER project. The proposed project would be the first to bring these groups together in an effort to address and improve patient-centered care for Native American tribes in Riverside/San Bernardino.

Engagement with Native American Communities

Many Native American Communities feel "...they have been researched to death" (8) without findings returning to the community (8, 22). With this persistent issue, researchers must first engage with the communities prior to writing research grants. Most importantly, the community must be full partners in

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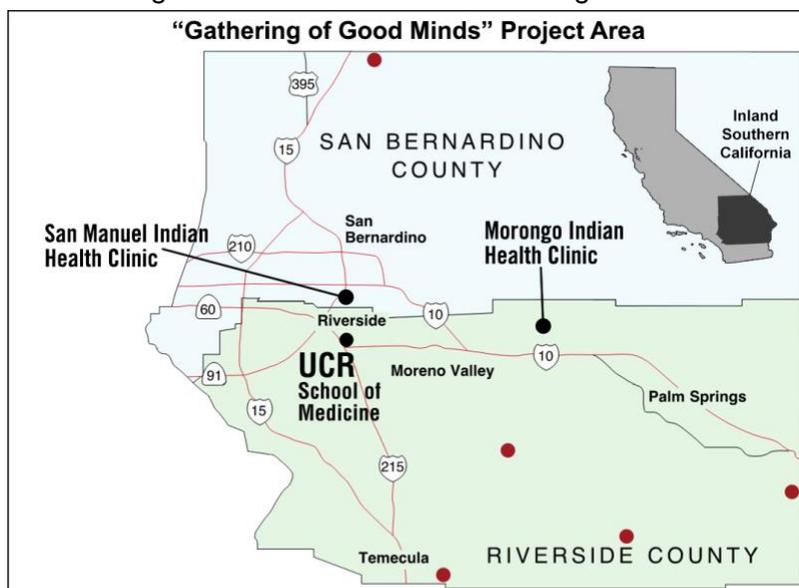
developing the research agenda, but cultural knowledge and the importance of intergenerational interactions, changes in health care delivery, larger political-economic relations, the role of genetics, and historical trauma all need to be considered and discussed as part of the sovereignty of Native American patients and communities (8,18-22). The Citizen Health Care Model (1) integrates these wide ranging concerns. Core principles of this model recognize patients, families, health professionals, community leaders, and policy makers as “citizens”, who are activated to “take ownership” of the problem when the knowledge and wisdom of their community is brought to bear on challenging health issues. This process is similar to the Brazilian educator Paulo Freire, whose work with disenfranchised communities (23) shifted community engagement toward thinking of how we can “read the world” and develop a consciousness that leads to engaged discourse, collaborative problem-solving, and social justice.

Objectives The short term goals of this project are to: 1) build a foundation of trust between the four stakeholder groups that would support future research, and 2) provide an opportunity for all stakeholders to gain knowledge and experience that would support future research. Beyond the scope of work for this project, longer term goals are to design and conduct a comparative effectiveness trial of culturally informed interventions to improve health of Native Americans (the specific topic will be chosen by our stakeholders in the final phase of this project).

Methods

Setting of proposed project

After consultation with the RSBCIHI Board, engagement activities will be developed at two clinics: San Manuel Indian Health and Morongo. The San Manuel Indian Health Clinic, located in the semi-urban city of Grand Terrace, is one of the newer clinics in the RSBCIHI consortium with a patient population including members of federally recognized tribes (many of whom live in the city, while others live on local tribal lands). The Morongo Clinic is located on the Morongo Reservation and the majority of patients live on tribal lands.



Proposed activities will principally involve stakeholders and patients at the Morongo Indian Health Clinic and San Manuel Indian Health Clinic, two of the clinic sites operated by Riverside San Bernardino County Indian Health, Inc. (RSBCIHI). Red dots indicate other RSBCIHI clinic sites.

Some expected commonalities in these communities are: the importance of intergenerational support, concern with community ways of knowing about food, and the impact of historical political and economic transformations on health and disease. Because the San Manuel Clinic is likely to have more participants living off of tribal lands, our engagement with these communities may document differences in their emphasis on the role of historical trauma and access to provider resources.

Project Organization
Leadership

The Academic Project Leader, Dr. Juliet McMullin, is a cultural and medical anthropologist with over 20 years of experience working with indigenous populations, especially Native Hawaiian

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communities, and is one of the few UCR faculty members with experience in community engaged research (24). In addition to her experience working with Native populations, she has collaborated with numerous medically underresourced communities (i.e., Latino migrants, Samoans and Tongans) in the United States. As the academic partner with Pacific Islander Health Partnership (PIHP), Dr. McMullin was recently awarded a Foundation for the National Institutes of Health, Heart Truth-Community Action Program grant titled *Navigating Pacific Hearts (NPH)*. The NPH award will allow the community to gather, adapt, and disseminate information about heart disease in Pacific Islander Communities as well as implement a dietary intervention. The NPH project and the proposed engagement project draw on Dr. McMullin's skill as an ethnographer trained to listen and contextualize lived experience, and ways of knowing and participating in the world for multiple groups. Her NIH funded projects on cancer and injury prevention have brought community members and medical practitioners into conversation with each other (25, 26). Dr. McMullin's work with Native Hawaiians, who have suffered many of the same intrusions on their sovereignty as Native Americans, and Latinas who have experienced racial discrimination in medical clinics gives her insight into the impacts social and historical factors can have on the health of these populations and how to use that knowledge to create a framework for more effective research and understanding of patient outcomes.

Dr. Kendall Shumway will serve as our Provider Project Leader. Dr. Shumway received his Doctor Of Podiatric Medicine degree from the California College of Podiatric Medicine; his clinical fourth year was spent at the University of Texas Health Science Center, internationally known for its Diabetic Foot Care Program. He completed his residency in General and Surgical Podiatry at the Carl T. Hayden Veterans Hospital in Phoenix, AZ. He grew up in Northern Arizona between the Navajo and Apache Reservations and has enjoyed his 13 years working in Indian Health. During the past seven years, in addition to overseeing two Federal Indian Health Service Grants for Heart Health and Diabetes Care, he has been the Diabetes Director at RSBCIHI. This program consists of three Diabetes Educators, two Fitness Specialists, a Medical Assistant, and a Family Nurse Practitioner who help oversee diabetes education and community outreach with the seven RSBCIHI clinics.

Our Community Project Leader, Luella Vann Thornton BS, MPH, RN, is retired; she was previously a Certified Health Education Specialist, and recipient of the 2011 California Rural Indian Board (CRIB) award for significant contributions to the health care of Native American groups. As a health educator, Ms. Thornton has taught parenting courses and counseling on drug addiction. Originally from Proctor, OK, Ms. Thornton is a member of the Ketoowah Band of Cherokee Indians.

Our RSBCIHI Project Leader, Sherri Salgado is the Vice Chair of the RSBCIHI Board of Directors and member of the Cahuilla Band of Indians. Ms. Salgado has been a delegate to the Riverside-San Bernardino County Indian Health, Inc. since 1999. As a member of the RSBCIHI Board of Directors she is part of the following Committees: Finance/ Planning Committee, Diabetes Task Force, and Wellness Committee. During her time at RSBCIHI she has seen the clinic grow and expand to offer new services, such as x-ray, mammography, behavioral health services, tele-health medicine and pain management. Her continual collaboration with RSBCIHI is integral to her being a part of improving Native American community wellness.

Dr. Sullivan, CHC director, will serve as an advisor for our leadership group. Dr. Sullivan has extensive expertise with community engaged research and guiding the collaboration of multiple stakeholder groups. She will be available for consultation and will attend APC meetings as needed.

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Action Planning Committee. The project will be overseen by a Gathering of Good Minds Action Planning Committee (APC) to be co-led by Juliet McMullin, PhD; Kendall Shumway, DPM; Luella Thornton, RN (retired), and Sheri Salgado, Cahuilla Band of Indians, RSBCIHI Board member. In addition to the four co-leaders, there will be eight members: two each selected from the leaders' respective stakeholder groups, for a total of twelve APC members. The APC will be broken down additionally as follows: three each will be: 1) UCR student and faculty representatives (i.e., Dr. McMullin; Sean Milanovich, Tribal Cultural Specialist for the Agua Caliente Band of Cahuilla Indians, PhD candidate in History at UCR; and Ann Cheney PhD, medical anthropologist and health services researcher), 2) health care providers (i.e., Dr. Shumway, Dr. Manuel Salmeron, RSBCIHI Medical Advisor and primary care provider at the San Manuel clinic, and Dr. Davis), 3) patient community members from the local tribes (i.e., Ms. Thornton, Pamela Atchitty, and Darren Henson), and 4) from the RSBCIHI Board (i.e., Sheri Salgado, Teresa Sanchez, and Clara Galindo). Nine of these 12 APC participants are members of one of the 12 federally recognized Native American tribes in Riverside/San Bernardino.

APC members will be asked to review and modify a previously prepared draft MOU that will lay out the role and purpose of the committee, the specific personal commitments members make, the monetary compensation for participating, and the duration of the commitment. During the first meeting, we will discuss approaches to address conflict resolution and consider approaches to improve continuity (e.g., having alternates stand in for busy APC members). The committee's primary purpose will be to provide guidance and oversight to participants in executing the project work plan. Subsequently, APC members will be asked to help recruit participants for fellowship meetings, and to provide advice on issues raised and discussed in the fellowship meetings. We encourage APC members to attend at least one Fellowship meeting. They may be involved in dissemination efforts and presentations in the community. The APC will meet monthly for the duration of the project; meetings would last 60-90 minutes. (See further information in the Engagement Plan.) The APC will be staffed by our project coordinator (TBN), in consultation with Ms. Christina Reaves. Ms. Reaves is an expert in co-leading and creating MOUs with community partners, and will work with the APC in developing processes to enhance equity within all stakeholder groups.

The APC meetings will take place at the two clinic sites on a rotational basis, allowing continued engagement with each clinic during organization and implementation of fellowship meetings at the individual sites. The APC will provide regular reports to the community (through social media, and/or a newsletter).

Fellowship Meetings.

The primary activity for the project period are the Fellowship meetings. Based on CHCM, these meetings have proven to be successful in Native American communities (1). The core principle recognizes the knowledge, wisdom and energy of individuals, families, and communities as the greatest resource for addressing health problems affecting their everyday life, and supports fundamental respect and focus on equal partnership between patients, providers, researchers, and policy makers. All our community partners and research faculty agree on the imperative to ensure Native American community voices are equal partners in every step of research development and implementation.

The CHCM provides a framework to insure equality in all processes of the engagement; working with the perspective that "...families are communities are producers of health and health care, not just clients or consumers, and that health professionals are citizens, not just providers." and "Citizens drive programs, rather than programs servicing citizens." (1, 27) This philosophy is resonant with Paulo Freire's (23) framing

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of education as a system wherein individuals are posed with problems relevant to themselves and the world in which they live and thus "...feel increasingly challenged and obliged to respond to that challenge. Because they apprehend the challenge as interrelated to other problems with a total context..." The Fellowship meetings will strive for a non-hierarchical engagement with community partners as equal citizens invested in solving real life problems and transforming our engagement with the social, political and economic context implicated as part of the problem preventing healthy communities and true partnership in research. Therefore, rather than providing specialized training for each stakeholder group, all stakeholder groups will be encouraged to participate in Fellowship meetings.

Requiring regular dialogue and engagement, fellowship meetings are designed to demonstrate a commitment to addressing problems identified by the community. Fellowship meetings are planned once a month for six months (i.e., six meetings at each clinic site) (1, 27); six meetings will occur at one site before a new series of meetings starts with the patient and provider group at the second site. Pre-proposal discussions among stakeholder groups guided us to hold fellowship meetings at the San Manuel and Morongo clinics as they allow us to consider not only differences between tribal affiliations but also consider structural impacts related to access to care in a semi-urban city (San Manuel) and on tribal land (Morongo).

Our first fellowship meeting will emphasize thinking about overall wellness and what Dr. Bonnie Duran (18) has called "soul wounds," part of the legacy of historical trauma impacting the health and wellbeing of many Native Americans. We have invited Dr. Duran to participate in the first fellowship meeting; she is an expert on community engaged research with an emphasis in mental health, addiction, and violence as they relate to historical trauma and health for Native American communities. Her work examines the impacts of intergenerational massive group trauma and historical unresolved grief on behavioral health (17,18). As the first event in our first fellowship meeting, we believe Dr. Duran's presence will demonstrate our commitment to engaging in difficult conversations as part of better knowing our stakeholder groups, building trust, and thinking about how to move forward together to address health issues. Dr. Duran will be invited to present her work at the initial meetings for both sites.

The remaining five fellowship meetings will be two hour long co-learning sessions (27,29,30). The first hour will focus on sharing and discussing individual and general experiences with health maintenance and health concerns in the community. Following the CHCM, the meeting begins with an equalizing activity. For example, in the CHCM everyone checks and records each others' blood sugars, weight, body mass index, and conducts foot checks. This activity is completely voluntary and not aimed at providing health services or risk screening, but rather to place everyone in an equal position as citizens caring for an identified health problem in the community. This activity is followed by active learning conversations based on the community regarding resources, knowledge and practices related to chronic disease prevention and care. This co-learning activity is particularly important for providers and students, as previous studies have shown that spending time outside of the clinic listening to patients' stories and sharing a meal with them extends health providers' knowledge beyond the clinic, enhancing their understanding of how to improve patient outcomes (28).

The second hour will use a "talking circle" format. Talking circles are an indigenous practice used for problem solving, teaching, learning, conflict resolution, and healing. Participants sit in a circle, allowing everyone to be seen and heard (29,30). The conversation begins with a set of predetermined questions or issues and everyone is invited to share their knowledge in a respectful manner. Talking circles may include

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such discussions as: the role of community gardens and local harvests for well-being, the importance of song and dance for intergenerational sharing, and the methods for addressing issues of historical trauma, to exploring what other tribes are doing to address chronic illness in their community, food as medicine, and having authentic discussions about research with Native communities. Talking circle topics will be determined by the APC in conjunction with fellowship meeting attendees. The first five talking circles will be facilitated by our project leaders, with the assistance of the RSBCIHI Behavioral Health Department. Dr. Clifford Trafzer will also provide historical and cultural expertise, and advice for conducting the talking circles. Once we have identified Citizen Leaders (described below), we will have these individuals facilitate the circle. Local healers and Native garden experts such as Roy Mathews (Native Healer) and Lorene Sisquoc (Native Gardens and Harvest Expert) will be invited to attend the meetings addressing their respective expertise. Dr. Sullivan and Ms. Reaves will attend talking circles where the discussion will include organizing community-engaged research and comparative effectiveness research. Talking circle topics are designed to address our goal of identifying stakeholders' key issues related to chronic illness prevention and care. This format creates a non-hierarchical form of sharing knowledge and trust building in identifying key issues (18, 23, 30, 31). Because all voices are heard equally, talking circles facilitate discussion of the complexities of wellness and impacts from the larger contexts of historical trauma and individual experience (18, 30). By considering the knowledge and practices associated with each topic, and what our stakeholder groups consider the most appropriate, effective, and sustainable practices, our talking circles would lay the foundation for CER.

Recruitment to Fellowship Meetings

Each stakeholder member on the APC will be responsible for inviting community members to fellowship meetings (e.g., health care providers invite other health care providers and patients interested in engaging researchers and community leaders in sharing and learning more about how they can use their knowledge and wisdom to collaboratively work toward finding solutions for the identified problems). Likewise, RSBCIHI and UCR faculty and students will invite their respective community members who would like to learn more and contribute to the conversation about what is important to Native American patient communities and how we can all move forward with effective research methods that would improve health outcomes. By following this recruitment strategy we will be able to access a broad range of community members in each stakeholder group who are impacted by, as well as decision makers in, the prevention and care of chronic illness.

Identifying Citizen Leaders

During the first series of Fellowship meetings we will identify up to four Citizen Leaders, with the intent of building their skills for continuity in community efforts with individuals trained in the CHCM as well as facilitating talking circles. These individuals will be from the patient population, have demonstrated a keen interest in addressing issues related to wellness and historical trauma, and shown an ability to collaborate with our various stakeholder groups. The Citizen Leaders, in collaboration with at least one of the project leaders, will hold Fellowship Meetings once a month for six months at the second site. This group will begin plans for the Wellness Summit and create plans for the next steps of our engagement.

Disseminating Findings from Fellowship Meetings

All Fellowship Meetings will have note takers who will summarize key issues and participant concerns. With participant and APC permission, we will post "lessons learned" and "issues raised" summaries in the clinics where the meetings are occurring; sharing our experiences with people who cannot attend and generating

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more interest in the project among clinic patients. Dissemination formats can include short briefs for pamphlets, social media (i.e., Facebook, Instagram, etc), or a photovoice or digital story-telling series. Most RSBCIHI clinic waiting rooms have Health Topic Video Monitors that can show the materials produced by our Fellowship meetings. Regularly sharing our engagement activities will demonstrate how researchers, community and clinics can work together to develop appropriate research questions and meaningful community agendas. Regular and timely dissemination of engagement activities is also a necessary step toward building trust between researchers and the community.

Research Ethics and CER Methods Training

At the end of the second series of Fellowship Meetings we will hold two community wide forums. These two forums will be designed to reintroduce research issues related to topics covered in the fellowship meetings. Discussions from the talking circles will be integrated into a forum on ethics and research, titled “What Really Matters.” We have invited Cynthia Pearson PhD, Associate Director for Research at the Indigenous Wellness Research Center, University of Washington, to participate in this forum. Dr. Pearson has extensive expertise in developing training and CITI manuals to assist researchers and Native American tribes in achieving their goals for implementing ethical practices in their research collaborations. A second forum on data measurement and outcomes will be titled “Ways of Knowing.” For example, using a standardized measurement tool, such as PROMIS, we will discuss the ethical and methodological intent. Building on the earlier conversations from our talking circles we can ask how the PROMIS tool fits the lived experience of our patient and community group, and how these questions and our talking circles can inform a more relevant way to assess and measure patient outcomes. As an expert in CER, Dr. Sullivan will guide the community research methods training.

Wellness Summit

The Wellness Summit will provide an opportunity for all stakeholder groups to gather, along with the two groups who participated in the fellowship meetings, to share their experiences and materials developed from engagement activities. This day-long event will include a summary of the project meetings. We will compile dissemination materials from the fellowship meetings and create a booklet to guide the community through our journey of learning about and from each other. Participants from the fellowship meetings will be invited to speak about their experience with the group, what was learned, and what is still missing. In this way we can acknowledge the accomplishments of the engagement with our stakeholder groups and solidify working groups for the next steps of our collaboration.

“Next Steps” Interest Groups

Based on the summaries from our Fellowship meetings and Wellness Summit, we will pull together interest groups during the final two months of the project. Ideally, participants will be from our stakeholder groups; we will add individuals, community leaders, or other appropriate representatives from institutions to fit the topic(s) the group would like to pursue. The purpose of these groups will be to discuss the next steps, including: which types of interventions might be appropriate to address the concerns, where such interventions should be located, and what funding sources might be available to support research in these areas. We expect these interest groups will act as “seeds” for future research projects, including comparative effectiveness research.

EXPECTED PROJECT OUTCOMES AND IMPACT

We expect this project will begin to address the problems outline in the first section of this application.

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Problem One: Need for intensive interaction and trust building. Through participating in this project, all stakeholder groups will engage with each other. In a safe and respectful environment, we will discuss the complex social and historical traumas that have impacted the lives and health of Native Americans. This regular and intensive interaction will lay the foundation for trust between our groups so that an authentic discussion can take place regarding if and how we will partner in patient-centered research.

Problem Two: Need to engage the perspective of the patient population and their community. Through the conversations at the fellowship meetings, we will have a greater understanding of the priorities and concerns of the local tribal patient population around chronic illness and contexts of wellness. This knowledge will guide the direction of our “interest groups” and future partnered research.

Problem Three: Faculty, students and clinic providers have little to no experience in Native American partnered research. Through our engagement in the fellowship meetings our stakeholder groups will have on-the-ground training with the CHCM, talking circles, active listening, and community building around the purposes of partnered, and patient-centered care research. This engagement will bring an understanding to our research community of the need to slow down the research process, listen to, and to make community members equal partners from the first step of considering a research project. With our APC, and collaboration with faculty and students at the SOM and across campus, we will have trained a new cohort of individuals who will be able to engage in community and patient-centered CER.

Problem Four: Provider clinic and patient population has no experience in comparative effectiveness research. Through our engagement in the Fellowship Meetings, Community Forums, and presentation on historical trauma, our provider and patient groups will be able to see the connections between their own contextualized lived experience and potential questions to be asked and methodologies to be used in CER. Both the intensive engagement and the linking of their own concerns and participation in creating the research questions will provide knowledge and skills to make decisions about if and how they will participate in CER.

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B. Timeline (Limit 2 pages)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Action Planning Committee																				
Planning Fellowship Meeting: General Topics Training for Talking Circles																				
Recruitment to Fellowship Meetings																				
Fellowship Meetings - Series 1																				
Dissemination of Talking Circle Conversations - Series 1																				
Identify and recruit Citizen Leaders																				
Make Any Changes for the Second Series of Fellowship Meetings																				
Recruit for Second Series of Fellowship Meetings, additional training for Citizen Leaders																				
Fellowship Meetings - Series 2																				
Dissemination of Talking Circle Conversations - Series 2																				
Develop Community Wide Forums																				
Two Community Wide Forums																				
Prepare & Host the "Wellness Summit"																				
Review, Summary, Evaluation, and Next Steps Interest Groups																				

There are three main activities for this project. The Fellowship meetings and talking circles will be led by Drs. McMullin and Shumway and Ms. Thornton. The Community wide forums will be led by Dr. Sullivan and Ms. Reaves. The "Wellness Summit" will be led by Ms. Thornton, Dr. Shumway, and Ms. Salgado. The Action Planning Committee (APC) will meet throughout the 20 months of the project. The first month will be spent developing and revising a draft MOU for the APC, setting ground rules, discussing conflict resolution, and reviewing the timeline and expected activities. Prior to each meeting the Project Leaders will prepare an agenda and materials and send them to the APC. In this way, members who want to add an item to the agenda have an opportunity, and our time at the APC meetings would be used efficiently. The APC meetings will rotate between the San Manuel Clinic in Grand Terrace and the Morongo Clinic in Morongo. APC meetings are open to the community.

The primary goal for Year 1 is to prepare, recruit, and conduct the first series of Fellowship meetings. As described in the application, the APC will develop topics and train to facilitate the talking circles. The APC will also be in charge of recruiting participants from their respective stakeholder groups for the Fellowship meetings. We estimate preparing for the Fellowship meetings would two months. The Fellowship meetings will occur once a month for six months, for a total of six meetings. Each Fellowship meeting requires considerable preparation (e.g., recruiting and publicizing the event, ordering refreshments, and developing the dissemination material). At the end of each Fellowship meeting, Dr. McMullin and Ms. Thornton will discuss the issues to be included in the dissemination material, which will then be produced and distributed to the clinics and stakeholder groups by our project coordinator. Dr. McMullin, with assistance from other investigators on the team, will lead the oversight of the Fellowship meetings.

During Series 1, we will identify and train Citizen Leaders from the first series of Fellowship meetings. Having participated in the six talking circles, the Citizen Leaders will have engaged in experiential learning. Dr. Cheney and Ms. Reaves will complement their learning by providing formal focus group and conversation facilitation training, which will include a half day workshop on the fundamentals of facilitating focus groups and a practice session. Members from the APC or other stakeholder groups will also be invited to participate in this training session. The Citizen Leaders will continue the once a month Fellowship meetings at the first site with the assistance of at least one Project Leader.

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At the end of Year 1 and through the first half of Year 2 we will conduct the second series of Fellowship meetings. Based on the experiences from the first series of Fellowship meetings, we will make adjustments to our process and the dissemination of materials. As in the first series of meetings, we will rely on the APC for recruitment and advertising which will occur over a one month time frame. Review and dissemination will follow the same general process as the first series of meetings.

Community wide forums on research methodology and ethics will occur in Year 2. We will use the dissemination materials from our Fellowship meetings to frame two four hour forums on “What Really Matters,” which will provide the basics for the ethics of research and a forum on “Ways of Knowing,” which will provide the basics on methodologies for comparative effectiveness research. These forums will be led by Dr. Pearson, and Dr. Sullivan and Ms. Reaves, respectively. These two forums will integrate conversations from our Fellowship meetings to provide examples of the different ways researchers, patients, providers, and institutions think about these issues and to seriously consider how to integrate Native ways of knowing and living in relationship to each other as truly mixed-method research practices.

The last few months of the project will be devoted to our “Wellness Summit,” evaluation, and next steps. The “Wellness Summit” will be a one day event that includes presentations from Fellowship meeting participants about what they’ve learned about health concerns and patient care, and how their perspectives have shifted on the role of their stakeholder group on how to engage each other in patient centered care research. Materials that are a product of the Fellowship meetings, such as the dissemination materials shared throughout the course of the project will be compiled and shared. We will also acknowledge the efforts of our APC and stakeholder groups who dedicated their time and knowledge toward the success of the project. At this meeting we will also identify individuals from each stakeholder group who have a keen interest in developing comparative effective research. Organizing speakers and developing the materials to be shared will take at least three months.

Evaluation of the project meetings and dissemination materials will form the basis for our “next steps” conversation, which will occur over the last three months of the project. By this time we will have identified if and how we can collaborate on patient centered care research and possible funding sources to which we could submit an application.

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C. Project Deliverables (Limit 2 pages)

YEAR 1		
DELIVERABLE	DESCRIPTION	PROJECTED DATE
1. Interim Report	PCORI-Required Project Report	November 2016
2. Action Planning Committee MOU	Document collaboratively written with the APC that describes the commitment and responsibilities of the APC members. The document would also include their compensation for their time.	June 2016
3. Fellowship Meeting Format	Description of the format for the Fellowship meetings – developed in collaboration with the APC	August 2016
4. Talking Circle Guide	Document used to facilitate the talking circles and the topics to be covered. Authorship is in collaboration with the project leaders and trained facilitators	August 2016
5. Dissemination Materials – Series 1	Dissemination of issues raised at Fellowship meetings. Would be authored by Dr. McMullin, Ms. Thornton, the project coordinator	January 2017
6. Interim Report	PCORI-Required Project Report	April 2017

YEAR 2		
DELIVERABLE	DESCRIPTION	PROJECTED DATE
1. Interim Report	PCORI-Required Project Report	September 2017
2. Adjustments Made in Talking Circles	Document addressing needed changes and explanations for why an activity was successful or not. Drafted by the project leaders in collaboration with the APC	March 2017
3. Dissemination Materials – Series 2	Dissemination of issues raised at Fellowship meetings. Authorship would be by Dr. McMullin, Ms. Thornton, and the project coordinator	August 2017
4. Community Forum Guides	Report on key issues to be discussed at the Community Research Forums. Authored by Dr. Sullivan, Dr. Pearson in collaboration with the project leaders	August 2017
5. Dissemination Materials - Summit	Flyers, presentations, and manuscripts	October 2017
6. Final report	PCORI-Required Project Report	December 2017

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Narrative Summary of Project Deliverables (Optional)

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D. Patient Engagement Plan (Limit 2 pages)

There are four primary stakeholder groups for this project; UCR faculty, researchers, and students, health providers, the Native American patient community, and Riverside/San Bernardino Indian Health Inc. (RSBCIHI). A key goal of our project is to bring these groups into a non-hierarchical conversation where we can learn about each group's expertise with a shared vision of contributing to patient-centered outcomes research to alleviate the health inequities experienced by Native Americans in the United States. Our initial engagement began with Dr. McMullin and Dr. Shumway meeting and developing patient-centered community grants. During these first steps we were joined by Dr. Trafzer and the RSBCIHI board. The creation of the Center for Health Communities (CHC) has brought the support and expertise to the UCR campus to fully engage the local community in the collaboration that began four years ago.

Action Planning Committee (APC). As described in the workplan, the APC is the key to greater outreach for engaging all of our stakeholder groups. Each project leader has identified three leaders from their respective stakeholder groups. We have insured that nine of the twelve APC members are Native American and from tribes in the RSBCIHI service area. The make up of this group represents a broad network of community members and professionals who are invested in improving the health of Native American communities. The APC members will participate to one meeting per month, advise on project activities, and to assist in advertising and recruiting for project activities.

Engaging Native American Patient Communities. While the Fellowship meetings are inclusive of all of our stakeholder groups, we expect greater participation from community members. The Fellowship meetings will engage the local Native American community in both its opportunity to learn about chronic illness and historical trauma research and what other communities are doing to address the issue, and to share their own experiences and knowledge of wellbeing and chronic illness in their community. In this way their engagement is critical to building trust and educating the research, provider, and RSBCIHI communities. The Native American patient community will be engaged through the Fellowship meetings (once a month for twelve months), Community Research Forums (two half day forums), and Wellness Summit (one full day). Select members from this community will increase their engagement through participation as Citizen Leaders, and as presenters at the Wellness Summit. This community will receive announcements about the project through RSBCIHI, their health care providers at RSBCIHI, and through project leader presentations at community events.

Engaging students. UCR require student involvement in community projects and our new SOM requires students to participate in Practice Improvement Projects. We expect to provide information to students about opportunities via internal communications at each of these institutions and create our own student listserv. The students on our APC will also assist in engaging other students. We will identify and train students to serve as Fellowship meeting assistants for the check-in portion of the meetings and as talking circle facilitators. Students will have an opportunity to participate in the training for the Citizen Leaders, and in the Community wide research forums. We will identify one or more students to assist with dissemination activities by creating and maintaining a Facebook page for the project, and we will Tweet during community forums and our final community-wide dissemination meeting.

Engaging Faculty. Several UCR faculty are already engaged with the new CHC, particularly from the College of Humanities, Arts and Social Sciences. Approximately 70 faculty are on the CHC listserv, many of whom

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have attended our retreats. Dr. Trafzer, who has been on the faculty for over 25 years, and Dr. McMullin will assist us in identifying additional faculty members to participate in the Fellowship meetings and the Community wide research and ethics forums. Faculty will also be engaged as members of the APC. We plan to make presentations about our project for appropriate campus groups, such as the UCR Native American Student Association and the California Center for Native Nations (CCNN). The proposed project will also be publicized through the CHC and the CCNN seminar series that brings speakers to the UCR campus and community sites.

Engaging Health Providers. Similar to our engagement with the Native American patient population we will engage health providers through our fellowship meetings, workshops, and summit. The Fellowship meetings will engage health providers in both its opportunity to learn about chronic illness and historical trauma research and what other communities are doing to address the issue, and to share their own experiences and knowledge of wellbeing and chronic illness in their community. The health provider engagement is critical to building trust with the patient community, and expanding their knowledge of community-based and patient oriented research. Health providers will be engaged through the Fellowship meetings (once a month for twelve months), Community Research Forums (two half day forums), and Wellness Summit (one full day). We will investigate the potential of offering health providers Continuing Medical Education credit for attending the fellowship meetings and the workshops. This community will receive announcements about the project through RSBCIHI board members and UCR community-based clinics.

Engaging Riverside/San Bernardino Leadership. With the participation of tribal leaders and Board members from RSBCIHI, we will regularly disseminate information about the project and our engagement efforts to tribal leaders, city councils, county board of supervisors, and other health-related groups that serve the needs of the Native American population. These leaders will be invited to our final dissemination event, the Wellness Summit.

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PROTECTION OF HUMAN SUBJECTS

For additional guidance, refer to [Section 5.0, "Human Subjects Research Policy,"¹ from the Supplemental Grant Application Instructions for All Competing Applications and Progress Reports, from the U.S. Department of Health and Human Services.](#)
 Use continuation pages as needed.

Describe the protection of human subjects involved in your project, if applicable.

Protection of Human Subjects

Gathering of Good Minds is an engagement project that will lead to future research. If funded, we will seek a determination from the UC Riverside IRB regarding the level and type of oversight necessary to carry out the engagement activities.

Risks to Human Subjects

Justification for involvement of human subjects

The purpose of the project is to engage with a system of care, providers, patients, and members of the community around the topic chronic illness and wellness in order to build the capacity to partner in future patient-centered research. The engagement activities include the convening of an Action Planning Committee (APC), Fellowship meetings, Community Forums, and Wellness Summit.

The APC will consist of individuals who represent the stakeholder groups (providers, patients, and community members). The APC will convene monthly and will guide and provide input into the planning of the Fellowship meetings and Wellness Summit.

The two-hour Fellowship Meetings will meet once a month for six months at one site followed by a second series at another site. The purpose of the Fellowship Meetings is to provide a venue in which providers, patients, and community members can share the experience of learning about wellness, chronic illness, and related topics, such as historical trauma and food as medicine. Four individuals from the first series of Fellowship Meetings will be trained as Citizen Leaders to co-lead the second series of Fellowship Meetings with the project team leadership and content expert.

The Community Forums will be two workshops that will focus on (1) ethics and research and (2) data measurement and outcomes.

The Wellness Summit will be an opportunity for the APC and Fellowship meeting participants to share with others (providers, patients, and community members) what they learned from the engagement activities. Any material was created over the course of the project, such as recipe books or songs, they will be distributed at the summit.

¹ Available at http://grants.nih.gov/grants/funding/424/SupplementalInstructions.pdf#5_4_IRB_Approval

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Subject population

This project will engage individuals who may be: (1) providers in the Riverside San Bernardino Indian Health Services Inc. (RSBCIHI) system; (2) patients at one of the clinics operated by RSBCIHI; or (3) interested members of the community. All participants are likely associated with the clinics at Morongo or Grand Terrace where Fellowship Meetings will be convened. The four Citizen Leaders will be participants in the first series of Fellowship Meetings.

Participants in the Community Forums and Wellness Summit will not be limited to the stakeholder groups, but will likely be associated with RSBCIHI and the communities the system serves.

Inclusion/Exclusion criteria

All mentally competent adults (18 and over per California law) who are able to attend Fellowship Meetings, Community Forums, and the Wellness Summit will be included.

Vulnerable populations

The emphasis on this project is on providers and patients within the RSBCIHI system of care and individuals from the communities RSBCIHI serves. The selected community is predominantly Native American.

Sites

The APC meetings will be hosted by RSBCIHI in Grand Terrace.

The Fellowship Meetings will be hosted by the RSBCIHI clinics in Morongo and Grand Terrace.

The Community Forum sites are not yet determined. The APC and four Citizen Leaders will choose the venue.

The Wellness Summit site is not yet determined. The APC will plan the event and choose the location.

Sampling plan:

All participants in the engagement project will be adults.

The four Project Leaders will each identify two individuals who, along with the four Project Leaders, will serve on the APC.

Approximately 30 individuals will participate in the Fellowship Meetings. They will be drawn from the professional and social networks of the stakeholder groups (providers, patients, and community members).

Four Citizen Leaders will be identified during the first series of Fellowship Meetings by the project leadership in consultation with the APC.

Community Forum participants will likely be associated with the RSBCIHI system or part of the professional or social network of the APC or Fellowship Meeting participants. We expect approximately 30 people attend. The Wellness Summit participants will be engaged in the same manner as the Community Forums. We expect approximately 100 people will attend.

Research material, data, and information

We will not collect PII or PHI as part of this engagement project.

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We will take notes during the Fellowship Meetings. They will be used to summarize key issues and concerns expressed by participants. With the permission of the Fellowship Meeting participants and APC we will ask RSBCIHI leadership to post the summaries in the Morongo and Grand Terrace clinics.

As part of the Fellowship Meetings participants may choose to assess physical issues such as weight or checking feet for wounds. None of these will be recorded. The purpose of the assessments and sharing is to foster fellowship and are in no way intended as research.

Following all Fellowship Meetings, Community Forums, and the Wellness Summit, we may survey participants to evaluate the usefulness of the engagement activity. This may include basic demographics, knowledge gained, and overall satisfaction. The survey will be developed in collaboration with the APC.

Personally identifiable information

PII will *not* be collected as part of this project.

Notes taken during Fellowship Meetings will not record PII or PHI. Survey results from the Fellowship Meetings, Community Forums, and Wellness Summit will be reported in the aggregate.

All notes and surveys will be entered into a password-protected file on a secure server that only the project team members will be able to access. If this project is within the scope of oversight by the UC Riverside IRB, all project leaders and support staff will complete human subjects training and be certified prior to the collection of surveys or notes.

As part of the Fellowship Meetings participants may choose to assess physical issues associated with chronic illness, such as weight or checking feet for wounds. None of these will be recorded. The purpose of the assessments and sharing is to foster fellowship and are in no way intended as research.

Materials and Information

If the project is under the UC Riverside IRB purview, all material will be submitted to the IRB for approval prior use. We expect to develop surveys, recruitment material, and dissemination material.

Potential Risks

No physical safety risks exist in the engagement plan, as attending meetings are routine for many individuals. One possible risk might be that someone outside a meeting could hear from participants that a specific person attended or other details about the Fellowship Meeting, Community Forum, or Wellness Summit. However, due to the topic (research and chronic illnesses) the risk of this being harmful are negligible, and are reasonable considering the importance of addressing chronic illnesses among Native American populations.

Alternative Treatments or Procedures

Alternatives to all planned activities are to not attend, to leave at any time, to not participate in some aspect of the activity, or to remain silent.

Adequacy of Protection Against Risk

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Recruitment strategies:

The APC will consist of 12 individuals. The four project leaders will choose two people each. These will likely be individuals associated with the RSBCIHI system, patients living with chronic illnesses, or community members.

Approximately 30 individuals will attend the Fellowship Meetings. We will ask RSBCIHI system providers to invite patients and their families. The RSBCIHI Board members will invite key individuals in their communities. Patients will be encouraged to invite their families. And the academic project leader will invite UC Riverside faculty and students interested in community engaged research. We will ask the California Center for Native Nations and UC Riverside Native American Student Association to also invite members. We will likely develop fliers and email scripts in addition to encouraging a strong word-of-mouth effort to recruit.

Four Citizen Leaders will be identified from the participants in the first series of Fellowship Meetings. The four project leaders will consult with the APC on their choice before approaching the four candidates.

The same methods used to recruit for the Fellowship Meetings will be used for the Community Forums and Wellness Summit. We expect the participants in the Fellowship Meetings to be members of the community served by the Morongo and Grand Terrace clinics for practical reasons with the frequency and intensity of participation. The Community Forums and Wellness Summit will likely be attended more broadly.

Informed Consent and Waiver

We will request a waiver of signed informed consent and documentation of informed consent as these would create the only link of individuals to the project. If the UC Riverside IRB determines a verbal consent script is necessary, it will describe the project, engagement activities, and state that participation is voluntary. Since we are not collecting PHI, HIPAA Authorization is not needed.

Protections Against Risk

Data: We are not collecting data for the purpose of research. The summary of notes and survey data confidentiality will be ensured by: (1) not including PII or PHI, (2) maintaining all data and records in locked storage areas accessible to project staff, and (3) password protected computer data files. Participants will not be personally identified in any scientific reports generated by the study. All results will be presented in aggregate form. All project staff, will undergo training on the protection of human subjects in research.

Activities (e.g. Fellowship Meetings and Community Forums): While we cannot guarantee that no one at public meetings or groups discussions will mention what happened during the meeting or discussion, an effort will be made to ensure participants understand the need to consider whether or not it may be considered sensitive information.

Protections for vulnerable populations

While children may attend the meetings, their opinions will not be recorded or surveys accepted.

Medical/professional intervention

Although participants are unlikely to need medical or professional intervention during activities, if necessary an affected participant will be referred to the local hospital, provider, or social services, as appropriate.

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Importance of the Knowledge to be Gained

Knowledge gained through engaging stakeholders around the topic of chronic illness and historic trauma and research may lead to future research and interventions to improve prevention and/or care among Native American populations. We may also gain important insight into the process and success of engaging providers, patients, and communities using the Citizen Healthcare Model.

Potential Benefits

Participants may gain a greater understanding of (1) chronic illness and historical trauma, (2) the state research and interventions for various chronic illnesses, and (3) the patients and communities RSBCIHI serves.

The potential benefits to others is substantial. If we are successful in engaging the stakeholder groups and developing the trust and capacity to partner in future research, this project may lead to research designed to develop interventions to better prevent and treat chronic illnesses in Native American communities.

Planned Enrollment Reports

We can approximate participants in Fellowship Meetings, Community Forums, and Wellness Summit. We do expect the majority of participants will be providers in the RSBCIHI system, patients, community members and predominantly Native American.

Sources of Materials

Data will *not* be obtained for research purposes.

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SUBCONTRACTUAL ARRANGEMENTS

Use continuation pages as needed to provide the required information.

Based on the objectives of the proposal as described above, *A Gathering of Good Minds* will engage Riverside-San Bernardino County Indian Health Inc. (RSBCIHI) as a subcontractor. As part of the subcontract, RSBCIHI personnel from will: 1) participate in the Action Planning Committee; 2) provide support for and attend fellowship meetings and talking circles; 3) recruit community members to attend fellowship meetings; 4) assist in identifying the four Citizen Leaders; 5) disseminate findings from fellowship Meetings; and 6) take part in the Wellness Summit at the conclusion of the project.

Riverside-San Bernardino County Indian Health Inc. Established in 1968 and incorporated in 1974, RSBCIHI is a consortium of 9 of 12 federally recognized tribes in Riverside and San Bernardino Counties. RSBCIHI's mission is to provide culturally sensitive healthcare, respect the traditional customs of Indian Communities, and promote wellness and early intervention to achieve healthy lifestyles. RSBCIHI operates seven ambulatory and behavioral health clinics throughout its two-county service area, including the two proposed sites for the engagement activities: San Manuel Indian Health (6,750 active users) and the Morongo Indian Health (8,197 active users) clinics.

RSBCIHI is the largest Indian Health care system in the state of California and provides an extensive array of services: Medical (e.g., Primary Care, Pediatrics, Women's Health, Pain Management, Podiatry, and Wound Care), Dental, Optical, Laboratory, Pharmacy, and Radiology as well as an Outreach Program with Public Health Nurses and Community Health Representatives. It is a 501c3 non-profit and is governed by a board consisting of two elected representatives from each of the nine Tribes. Mr. Jess Montoya, CEO oversees the day-to-day operations of the corporation, while Dr. Karen Davis, MD, Clinical Director oversees seven clinics. Eligible patients are from the local tribes, but Native Americans from across the country and also non-Native spouses and immediate family members seek care at RSBCIHI clinics. RSBCIHI is a Federally Qualified Health Center and receives income through third party billing as well as directly from the Indian Health Service.

UC Riverside Subaward Policy

The subcontract for RSBCIHI will be handled through the Office of Research and Economic Development of the University of California, Riverside (UCR). Forms and approval may take place post-award; all terms and conditions required by the prime sponsor will be generated by the Office of Research and Economic Development and presented to the subcontractor by either the PI or the Contracts and Grants Officer assigned to the School of Medicine. Recipients of a subcontract or subaward may request clarification or negotiation of terms through the Office of Research and Economic Development, and the completed document, executed by both parties, will be available through UCR's Proposal & Award Management Information System (PAMIS).

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REFERENCES CITED

Each reference must include the names of all authors (in the same sequence in which they appear in the publication); the article title; journal or book title; volume number; page numbers; and year of publication. Include only bibliographic citations. Refer to the PCORI Engagement Awards application guidelines for additional help. Use continuation pages as needed.

Following standard citation practice, list the source material cited in your project plan, if applicable.

References

1. Doherty WJ, Mendenhall TJ. Citizen health care: A model for engaging patients, families, and communities as coproducers of health. *Fam Syst Health*. 2006;24(3):251. doi: 10.1037/1091-7527.24.3.251.
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 PROJECT LEAD: Juliet McMullin

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