

SOUTHCENTRAL FOUNDATION

Requirements of Researchers

Proposal

I. Overview

Approval of new research studies and dissemination of findings by Southcentral Foundation (SCF) requires that researchers meet certain standards established by the SCF Board of Directors and informed by community-based participatory research (CBPR). SCF has instituted these standards to ensure that research priorities are set by Alaska Native peoples in a manner that is culturally based and respectful due to the history of research with Alaska Native and American Indian (AN/AI) peoples. Researchers seeking approval from SCF are expected to carefully review this document and to complete a Requirements of Researchers Checklist with each submission.

II. History of Research with Alaska Native and American Indian Peoplesⁱ

The Indian Self-Determination and Education Assistance Act of 1975 (P.L. 93-638) codified self-determination of AN/AI peoples by enabling tribes and tribal organizations to contract directly with the United States federal government for health and education grants and thereby exercise greater control over their own welfare (Jones, 2006; Rhoades & Rhoades, 2014; Sherry, 2004). In addition to exercising the right to own and manage federally funded health services and programs under this process of self-governance (Barnard, 2015; Charlesworth, Jamieson, Davey, & Butler, 2015; Chino & Dubruyn, 2006; Gottlieb, 2013; Rajaram et al., 2014), many tribes and tribal organizations have established policies governing research with AN/AI community members (Chino & DeBruyn, 2006; Ferreira & Gendron, 2011; Jetter, Yarborough, Cassady, & Styne, 2015; Kelley, Belcourt-Dittloff, Belcourt C., & Belcourt G., 2013).

Research studies have concluded that AN/AI peoples distrust research (Buchwald et al., 2006; Christopher, 2005; Manson, Garrouette, Goins, & Henderson, 2004). Contributions to this distrust are multi-faceted and are intertwined with distrust of federal and other non-Native organizations, given their history of forced assimilation, discrimination, and other mistreatment. AN/AI peoples and communities have experienced harmful research, view most research as benefiting researchers but not AN/AI individuals or communities, and find sharing research results with respondents and communities lacking or unsatisfactory (Harding et al., 2012; Hiratsuka, Brown, Hoeft, & Dillard, 2012; Williams et al., 2010). Two research studies in Alaska are cited as examples of research that harmed the AN community and breached the trust between researchers and community members: the Alaskan I131 experiment and the Barrow Alcohol Study, both described in Dillard et al (2018).

III. Community-Based Participatory Research Standards

SCF requires all research meet key standards set forth by the SCF Board of Directors and based on the tenants of CBPR (Israel, Schulz, Parker, & Becker, 1998).

The AN/AI community is recognized as a unit of identity.

- Researchers will include an acknowledgement of appreciation for all participants of the study.
- Researchers will consider benefits and harms which extend beyond individual AN/AI participants to immediate and extended families and the AN/AI community.
- Benefits and risks will be carefully examined for potentially more vulnerable subgroups of the AN/AI community including elders, youth, and individuals who are incarcerated.

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- Research will include context of AN/AI peoples for the topic of investigation including the following list of considerations:
 - Historic and intergenerational implications of rapid assimilation
 - Cultural suppression
 - Lack of accessible healthcare
 - Boarding School (Removals) Survivors

Research will build on the strengths and resources within the community.

- Research will consider whose story is being told through the research and use language that is respectful of the person(s) story.
- Research must use language that is not construed as negative to AN/AI peoples, list provided for reference.
- Research will emphasize wellness, assessing strengths and protective factors in addition to pathology and risks.
- Research will consider multiple dimensions of health, including physical, mental, social, and spiritual health.

Collaborative partnerships are facilitated in all phases of the research.

- Research will focus on issues prioritized by the AN/AI community.
- Whenever possible, AN/AI peoples will be involved in the design and conduct of the research. Research on sensitive topics such as alcohol and substance misuse, domestic violence, suicide, sexual behaviors, death and dying, treatment of elders or children, and historical customs must include AN/AI co-investigators.

Knowledge and action are integrated for benefit, for science, and for Alaska Native peoples.

- The primary intent of research will be to benefit the health of and systems of care for AN/AI peoples.
- The time and energy devoted to research by AN/AI peoples as well as tribal healthcare systems are valuable and limited resources. Thus, the research project must be well designed and of sufficient importance to warrant investment of resources.

Research is a co-learning and empowering process that attends to social inequalities.

- AN/AI peoples will be appreciated, respected, and valued while participating in the research. Researchers will carefully consider language used in research protocols, measures, manuscripts, and presentations.
- Research will use a trauma-informed approach. A trauma-informed approach acknowledges historical and other forms of trauma, violence, and harm levied against AN/AI peoples. Researchers will be aware of current and past power differentials and promote safety, empowerment, transparency, and choice in the research process.

Research involves a cyclical, iterative process.

- Researchers will obtain SCF review approval at each step of the research process and address required changes or suggestions. Researchers will obtain approval of the general concept of the research project, the detailed methods and measurements present in the full research protocol, and any manuscript or abstract before publication and presentation.

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- Findings should inform subsequent research and/or healthcare system improvements.

Research addresses health from positive and ecological perspectives.

- Researchers will consider and include important social, economic, historical, political, and environmental factors in the research.
- Researchers will consider the impact to the psyche of AN/AI peoples when they are described as having more illness and more risk factors compared to other populations. Negative comparisons will be made only when necessary.

Findings and knowledge gained are disseminated to all partners.

- Research findings will be shared with AN/AI peoples as well as SCF employees and programs which may be impacted by the research findings.

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IV. Checklist

Investigators are required to consider each item listed on this form and provide a Y, N or NA response. If the item does not apply to your submission, please provide an explanation of why it does not apply. Please provide a detailed response to all questions that require further explanation or rationale. Your responses will help SCF Research Review assess the submission.

#	Research Requirement	Response (Y/N/NA)
Risks		
1	Benefits and harms to immediate and extended family and/or the AN/AI community as a whole are delineated.	
	If no or NA, please explain.	
2	Research will involve youth, elders, and/or individuals who are incarcerated.	
	If yes, please provide rationale for inclusion, potential benefits and harms, and additional protections.	
	If youth are involved, please describe how the research team will undergo and submit results of background checks and finger printing.	
	If youth are involved AND parental consent and youth assent will not be obtained, please provide a justification.	
3	Risks to privacy including inadvertent identification of participants given small sample sizes are identified and addressed AND standard privacy protections are used. Standard privacy protections include local retention of data and any collected specimens, destruction of all data and any collected specimens unless permission to store and retain data is obtained from participant, and a prohibition against presenting data from 4 or fewer participants.	

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#	Research Requirement	Response (Y/N/NA)
	If no or NA, please explain.	
4	The research involves sensitive topics such as, but not limited alcohol and substance misuse, domestic violence, suicide, sexual behaviors, death and dying, treatment of elders or children, and historical customs.	
	If yes, please describe efforts to minimize stigmatization potential, cultural, and other harms.	
	If yes AND the investigative team does not include AN/AI peoples, please justify the omission of an AN/AI investigator or co-investigator.	
Style		
5	AN/AI peoples and tribal affiliations are referred to according to required language. When working with people from a specific region use the terminology they are preferred as. Required language includes: 1) Unangaġ (Aleut), Sugpiaq (Alutiiq), Haida, Tsimshian, Tlingit, Yup'ik / Cup'ik/Cup'ig, Inupiaq, Dena (Athabaskan), Ahtna, etc. rather than Eskimo, Indian, Aleut. 2) When working with multiple regions, use the terminology Alaska Native peoples or Indigenous peoples.	
	If no or NA, please explain.	
6	Research will include context of AN/AI peoples for the topic of investigation including the following list of considerations: (1) historic and intergenerational implications of rapid assimilation; (2) cultural suppression; (3) lack of accessible healthcare; (4) boarding school (removals) survivors.	
	If no or NA, please explain	

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#	Research Requirement	Response (Y/N/NA)
7	The research considers whose story is being told through the research and uses language that is respectful to the person(s) story.	
	If no or NA, please explain.	
8	Required language is used to avoid language that could be construed as negative to AN/AI peoples. Required language includes: 1) research participant rather than research subject; 2) an individual with a positive test rather than infected; 3) an individual with an illness rather than disease; 3) an individual with substance misuse rather than substance abuse; 4) an individual with alcohol overuse rather than an individual with heavy drinking; 5) an individual with a behavior or diagnosis (e.g., individual who smokes, individual with schizophrenia) rather than an individual defined by a behavior or diagnosis (e.g., smokers, schizophrenics); 6) bacterium or virus rather than germs; 7) Alaska Native and American Indian peoples rather than Natives or Native Alaskans; 8) Using Alaska Native/American Indian (AN/AI) peoples when referring to studies that take place in Alaska and other states as well as studies in Alaska which involve customer-owners who are American Indian. 9) Customer-owner, patient, and Alaska Native community should be used in circumstances in which they are appropriate.	
	If no or NA, please explain.	

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#	Research Requirement	Response (Y/N/NA)
9	Statements and areas of focus are strengths-based (e.g., “increase the number of people who do not smoke” rather than “decrease the number of people who smoke”).	
	If no or NA, please explain.	
10	Language used assumes equal power between researchers and participants as well as providers and people they serve. For instance, compliance is a term which should be avoided as it implies that providers know what is best for the people they serve. Treatment plans should be co-created between providers and those they serve.	
	If no or NA, please explain.	
11	The first line of the narrative is strengths-based and does not state that AN/AI peoples have more illness and more risk factors than other populations.	
	If no, please provide a rationale.	
Methods		
12	The research emphasizes wellness, measuring strengths and protective factors in addition to pathology and risks.	
	If no, please explain.	
13	The research includes multiple dimensions of health (e.g., physical, mental, social, spiritual).	
	If no or NA, please explain.	
14	Materials describe how the focus of the research is a community-identified priority.	
	If no or NA, please explain.	
15	Provide details about engagement with the AN/AI community throughout the research.	
	If no or NA, please explain.	

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#	Research Requirement	Response (Y/N/NA)
16	The research includes a comparison group or control group.	
	If no or NA, please provide a rationale for the selected design.	
17	Results of a power analysis or other justification for the sample size are provided.	
	If no or NA, please explain.	
18	Limitations of the research design, methods, and knowledge gained are identified.	
	If no or NA, please explain.	
19	Rationale (e.g., narrative or conceptual framework) is provided with respect to the overall number of measures and measures selected particularly if the focus is on pathology and risk and questions are sensitive in nature (e.g., ask about diagnoses or behaviors with high stigmatization potential such as substance misuse or behaviors contributing to sexually transmitted infections).	
	If no or NA, please explain.	
20	Research practices which limit transparency and choice are avoided. Rationale is provided for research that uses deception or randomization.	
	If no or NA, please explain.	
21	Consent for storage of data in a repository, and long term storage of specimens is obtained separately from consent to participate in the overall study.	
	If no or NA, please provide a rationale.	
22	Consent forms and other participant materials are written clearly and limit technical jargon.	
	If no or NA, please explain.	
23	The physical and emotional safety of participants is considered and prioritized. For instance, if questions are posed about traumatic	

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#	Research Requirement	Response (Y/N/NA)
	events, risks of emotional distress are identified, and a plan is in place to respond to the distress.	
	If no or NA, please explain.	
24	Succinctly describe why your research project is necessary, what problem it is addressing and why its valuable to AN/AI peoples.	
25	For approval to deposit data into any data repository, please provide a formal request to include each repository, a rationale for why the request is being put forward, how it would be of benefit to the Alaska Native community, how would those data be protected and how and who will ensure that SCF BOD approval is sought prior to any secondary analysis. Include Data Use Agreements with sub-awards and Data Management and Sharing Plan.	
26	SCF is included in any data access committee approvals and reviews any data access requests.	
	If no or NA, please explain.	
27	Were any AI tools used to develop research materials?	
	If yes, please provide and explain the source and type of AI used.	
Resources		
28	The research will produce financial benefit.	
	If yes or NA, please explain.	
29	Any financial benefits produced by the research will be shared with the AN/AI community.	
	If no or NA, please explain.	
30	Potential improvements to the health of and/or systems of care for AN/AI peoples are delineated.	
	If no or NA, please explain.	

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#	Research Requirement	Response (Y/N/NA)
31	If healthcare system resources are required for the research project, there is evidence that the healthcare system has agreed to invest these resources and/or the budget includes appropriate compensation.	
	If or NA, please explain.	

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ⁱ Adapted from several SCF publications, including: Dillard, D. A., Caindec, K., Dirks, L. G., & Hiratsuka, V. Y. (2018). Challenges in engaging and disseminating health research results among Alaska Native And American Indian people in southcentral Alaska. *American Indian and Alaska Native Mental Health Research (Online)*, 25(1), 3-18. doi:<https://doi-org.ezproxyhhs.nihlibrary.nih.gov/10.5820/aian.2501.2018.3>