

Responses to SCIA Roundtable Questions

April, could you speak to the importance of Indigenous data sovereignty—what it means in practice—and how Southcentral Foundation is approaching data collection and use to support your mission?

- Indigenous data sovereignty is the right of a Native nation to govern the collection, ownership, and use of its own data.
- It is the right of Alaska Native peoples to own, control, access and possess data that derive from them, and which pertain to their members, knowledge systems, customs or lands.
- In the Alaska Tribal Health System, data governance includes data related to the cultures, belief systems, traditional healing, health behaviors, healthcare services, individual diagnoses and treatments, biological specimens, and our genetic make-up.

SCF's approach to Indigenous Data Sovereignty

- SCF supports personal and individual data privacy protections for Alaska Native peoples
- SCF also supports Alaska Native peoples data sovereignty through the development and management of collective data privacy protections, supported via community-controlled data infrastructure, which are essential to ethical Indigenous data practices
- SCF has developed policies and procedures to ensure that data collection occurring with customer-owners and at SCF health facilities is aligned with Alaska Native values, interests, and priorities
- SCF utilizes a research review process that Tribal leaders developed
- SCF's Alaska Native Institutional Review Board exercises the right to decide what data is collected, how the data is collected and who has appropriate access to data collected
- 2800+ SCF staff members support self-determination in Alaska Native data collection, use and meaning making daily as we develop, enhance and utilize respectful data governance, storage, security, and support Alaska Native value-based decision-making with this data.
- Within public health surveillance, SCF health programs determine what data could and should be shared with federal, state, and other partners when evaluating health programs and monitoring population level health outcomes and behaviors.
- Within health research, our Board of Directors, with support from our Research Department review each proposed research project, with review at each phase of the research project lifecycle, to ensure that Alaska Native data is collected appropriately, is protected, secured, and used in a manner that directly benefits Alaska Native people and does not harm, at an individual, family or community level.

What it means

- Indigenous data sovereignty practices in use at SCF have increased customer-owner's trust in health care providers, health programs offered to customer-owners, and participation in health research.
- We have increased privacy and confidentiality by checking on the use of each identifiable data point in the analysis and in reporting.

- Importantly, health surveillance data is able to be contextualized. Communities and the health programs supporting their wellbeing now oversee how stories about them are being created, framed, and told.
- We have been able to more accurately report the fullness of customer-owner health by requiring data collection including qualitative data, along with health outcome data points.

April—our proposed legislation includes provisions to carve out Tribal set-asides within several key state block grants, ensuring Tribal health organizations have direct access to the resources needed to serve their communities. Can you speak to the importance of these set-asides and the impact they could have on Tribal health systems?

- Tribal set-asides honor the importance of self-determination, ensuring funding goes directly to Tribes and Tribal Organizations.
- Without set asides, Tribes and Tribal organizations compete in the same grant application pools as other organizations—which creates two obstacles.
- First, Tribes & Tribal organizations are forced to.
- adapt our applications and programs to be competitive with other interest groups, which often makes them less effective at actually solving problems in our communities.
- Second, state granting agencies often ask Tribes and Tribal organizations to waive their sovereign immunity to obtain the grant funding that is being passed through the state from the federal government.
- Grant agency restrictions, while often well intended, can cause barriers to good interventions in Tribal organizations. For example, a grant may prohibit funding food at community events.
- Sharing in traditional foods is a vital part of Alaska Native culture and is a good way to bring communities together for important health related issues. Tribal set-asides provide maximum flexibility to Tribes and Tribal Organizations in line with self-determination and allow us to ensure funds are spent in the best, culturally appropriate ways.
- For all of these reasons, the Tribal set-asides in block grant programs for Social Services, Child Abuse Prevention and Treatment, Child Health Services, Community Mental Health, Substance Abuse Prevention, Treatment, and Recovery, and Child Care and Development are critically important.
- Increasing the amount of funding coming to Tribal communities through block grant set-asides, and through self-governance and self-determination mechanisms has the potential for generational change on so many important areas of life and community.

Thank you and the committee for your leadership in this area—your commitment to the health and well-being of Alaska Native and American Indian children is so appreciated.