



UNIVERSITY OF WASHINGTON
CENTER FOR GENOMICS & HEALTHCARE EQUALITY

REFLECTIONS on PARTNERING in GENETIC RESEARCH

This handout provides questions a tribal leader or agency might reflect upon when considering partnering with investigators or research organizations on projects that involve genetics research. The document was designed with the assumption that a tribal group has decided to participate in genetics research and is seeking general guidance on critical topics for discussion when evaluating a potential research partner. The list is not meant to be exhaustive, but rather can be used to initiate reflection and sharing of the values that drive the research planning and process.

COMMUNICATIONS

- **Are you comfortable sharing your experiences, perceptions, hopes, and fears for genetic research with the partner? Does the partner acknowledge these as valid views that should be considered in light of the research protocol?**
- **Are you able to provide the partner with constructive feedback that may lead to improved communications and understanding?**
- **Does the research partner take time to listen to your concerns? Are they a learner in this relationship? ...a teacher?**

TRUST

- **Do you think your tribe/agency will benefit from working with this potential partner? Does the partner's vision of benefit for your tribe/agency participating in genetic research overlap with yours?**
- **Do you share common values that can lead to a mutually respectful relationship?**
- **Have you discussed any assumptions you have about your expectations from the partner? ...their institution? ...the funding agency? ...the research?**
- **Is there a plan for discussing the results of the research with tribal leadership? Is the research partner considering ways to present genetic results that can be understood and accessible to the community (ie. curriculum, video, informal dialogue or question/answer session)?**

CONTROL

- **What plans does the partner have for collecting, storing, tracking use of biospecimens (blood, tissue, etc) in this project? Are they asking for your input on these processes?**
- **What degree of responsibility (if any) would your tribe/agency want in controlling collection, storage, tracking biospecimens? Are you able to seek out and receive assistance from a partner in building this capacity for your tribe/agency?**
- **Does the partner consider secondary use of research data or sharing of biospecimen samples a new project that requires tribal review and approval?**
- **Is appropriate effort, time, and funding included in plans for tribal review of dissemination products such as publications?**