A Collaborative Research Partnership Between the Salt River Pima-Maricopa Indian Community and the Translational Genomics Research Institute
SRPMIC was committed to finding solutions that would impact the prevalence of diabetes and resulting complications from the disease.

- Partnered with Tgen
- SRPMIC developed a way to express sovereignty over research through the contract and research code, which are model template documents.
- SRPMIC drove the research question and that is important
- SRPMIC has been very deliberate in determining how research should continue
• Research idea presented to TGen by SRPMIC Medical Director and Health staff based on clinical observations:
  - Significant number of patients diagnosed with renal cell carcinoma (RCC).
  - Unique research question due to incidence, gender and age.
• Joint study developed to evaluate the impact of RCC (kidney cancer) among community members. Study formally approved by Tribal Council.

• Research Plan and Research Collaboration Agreement signed in 2007 (also includes Material Transfer Agreement and Intellectual Property Agreement). TGen laboratory areas and staff blessed by Tribal elder.

• TGen consulted with SRPMIC Medical Director and Health Staff throughout the course of the study analyses and requested approvals as needed.

• Study data preliminarily discussed with the Medical Director and Health Staff. Additional options discussed and approved by Council to potentially continue study and validate findings.
Documents in Place

- Research Collaboration Agreement
- Material Transfer Agreement
- Intellectual Property Agreement
- Research Plan
- Informed Consent Form
- Hospital Transfer
Community and TGen are to perform collaborative research

TGen can only perform research that is expressly authorized in Research Plan.

Revenues from a Sole Invention and a Joint Invention will be shared equally by Community & TGen.

All Results and Data will be jointly owned.

Community can terminate at any time and Research Material will be returned to the Community on request.

TGen may not disclose “Confidential Information” to third parties.
- No distribution of Research Material (specimens) to third parties without prior Community and individual authorization.

No publication by TGen without prior written authorization of Community.
Agreement provides for a Limited Waiver of Sovereign Immunity for the purposes of authorizing binding arbitration and judicial action before the U.S. District Court or Maricopa County Superior Court if the U.S. District Court lacks jurisdiction.

Judicial actions are limited in scope and are only to encompass pre–arbitration injunctive relief, enforcement of a duty to arbitrate or enforcement of an arbitration award.
Material Transfer Agreement

- Research Material is owned by the Community.
- Upon completion of research, TGen obligated to return or dispose of Research Material as directed by Community.
- TGen can only use Research Material in strict conformance with the Research Collaboration Agreement.
  - Documents what Research Material is transferred to and accepted by TGen.
Research Plan

- Jointly Developed Scientific Protocol
- Outlines Technical Aspects of Study
**Informed Consent Form**

- Form used to notify Community member of the risks and benefits of participation in the study
- Includes protections for:
  - Confidentiality
  - Biological Specimens
  - Participant Rights
Considerations

- True Partnership – Open Communication (respect and working to understand one another)
- TGen has kept the IRB paperwork up to date
- Very tight agreement, can impact research (Strong Heart)
- Staff Time to participate in the study
- Assuring that the contract is adhered to
Next Steps for SRPMIC

- Further Development of Research Commissions
- Continue to partner with TGen
  - Development of youth to be scientists
  - Articles in Community paper
  - Presenting information regarding various diseases, in particular diabetes