



“Unique Characteristics of Tribal Communities and the Impact on Cancer Control”

2016 AI/AN Cancer Summit

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Know your target community

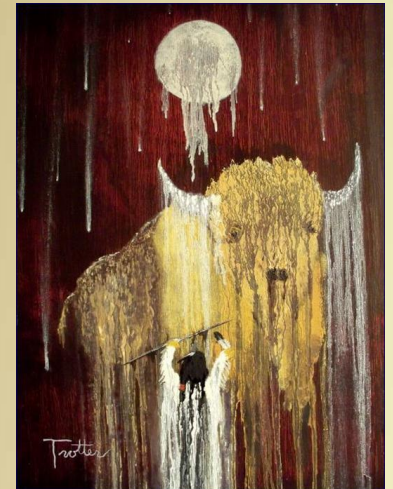
- visit and talk to the people
- talk to the health board, tribal council..
- explore existing cancer programs and infrastructure
- don't assume things ...my University
- what are the tribal needs and what do they really want or not





Know your target community

- Previous studies done.. Redundant
- Think outside the box.. Internet, phone service
- Find out what was working in successful past projects... be **POSTIVE**





You need a CAB

Community Advisory Board

- help to understand uniqueness of the tribe and their history
- help in designing the project
- help in answering ethical, religious and social questions
- will help to resolve barriers and problems while doing the project
- hire local for food, staff
- will help to find local staff



Give project updates to Health Board, Council and the Community

- Be transparent and visible TRUST
- Give routinely updates regardless if there are any news
- Come yourself if possible ... face value
- Double check time, place and meeting



Research studies



- Research studies involving people
- Try to answer scientific questions and find better ways to prevent, diagnose and treat disease
- What IRB is needed,
- Who owns the data? Can I publish?
- What to do with left over samples?
- How and where to store data and samples safe



Barriers

- Cultural knowledge
- Time and distance
- Weather
- Tribal politics







Unique Characteristics of HPV-STD's on Impact on Cancer Control

- A lot of tribal members don't like to talk about HPV, HIV, sexual behavior or STD's
- Be careful in disseminating this sensitive information
- Problem, we need data to justify interventions
- Interventions: respect tribal norms, Mixed boys – girls education ?

Patient Protection

- There have, unfortunately, been past abuses in patient protection
- Federal regulations ensure that people are told about the benefits, risks, and purpose of research before they agree to participate





How Are Patients' Rights Protected?

- Informed consent
- Scientific review
- Institutional review boards (IRBs)
- Data safety and monitoring boards (DSMBs)



How Are Patients' Rights Protected?

Data and safety monitoring boards:

- Ensure that risks are minimized
- Ensure data integrity
- Stop a trial if safety concerns arise or objectives have been met



THANK YOU

Friday, September 30, 2016 Friday

<http://gfp.sd.gov/state-parks/directory/custer/events/buffalo-roundup/> !

