Objectives: By the end of this 1 hour session, the meeting participant will be able to:

1. Identify common misinformation about community partnerships with American Indian (AI) populations.

2. Delineate between successful and unsuccessful strategies for effective and respectful partnerships with AI Nations and individuals (some concepts will be repeated to reinforce learning).
A Few Cautions

AIAN cultures (465+ federally-recognized plus, 200+ state-recognized tribal Nations)
- Share some commonalities
- But, basically each tribal Nation has unique characteristics
- EVEN within this local state

Common Values Among Natives

- Sharing and generosity
- Allegiance to family, community, and tribe
- Respect for elders
- Non-Interference
- Orientation to present time
- Harmony with Nature
- Respect for status of the Woman and the Child

Carol Locust, Univ AZ, Tucson
Cultural Considerations in Community Based Research

Common beliefs related to Spirituality

- A belief in an unseen power, Great Mystery or Creator
- All things in the universe are related
- Worship reinforces bonds between the individual, family, and community (our relatedness)
- Spirituality is intimately connected to our health

Respective Core Values

<table>
<thead>
<tr>
<th>Traditional Native</th>
<th>Main Stream US Society</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cooperative</td>
<td>Competitive</td>
</tr>
<tr>
<td>Group/Tribal Emphasis</td>
<td>Freedom, Progress, Efficiency</td>
</tr>
<tr>
<td>Extended Family Important</td>
<td>Individualism</td>
</tr>
<tr>
<td>Modesty</td>
<td>Sexy</td>
</tr>
<tr>
<td>Patience/Passive (SW)</td>
<td>“Getting Ahead in Life”</td>
</tr>
<tr>
<td>Generous/Non-Materialistic</td>
<td>Material Comfort</td>
</tr>
<tr>
<td>Respect for Age</td>
<td>Youth Envy</td>
</tr>
<tr>
<td>Spirituality</td>
<td>External Conformity</td>
</tr>
<tr>
<td>Indirect Criticism</td>
<td>Direct Criticism</td>
</tr>
<tr>
<td>Harmony with Nature</td>
<td>Conquest of Nature</td>
</tr>
</tbody>
</table>

Burhansstipanov, Native American Cancer Research
A Few Cautions

Traditional AIANs perceive “life” and prioritize factors quite differently than do general US society

This does not mean:
- We are dumb
- We will not follow Western Medical Protocols

Background: Tribal Sovereignty

- Tribes are governments that have authority with regard to their members
- Tribes existed prior to the U.S.
- Tribal Nations made treaties with colonial powers, states, and the U.S.
- Nations within a nation
Cultural Considerations in Community Based Research

Background: Government-to-Government Relationship

- Tribes are treated as governments by the federal government.
- Approval Protocols
  - Tribal "consultation"= means federal agency must meet with all 564+ federally recognized tribal Nations …
  - Cannot meet with selected Nations or groups and meet the legal definition of "consultation"

Culture-wide Multiple Traumas

- Racism/Poverty
  - Addiction
  - Depression
  - Post Traumatic Stress Disorders
  - Neglect/Abuse of Children "Inadequate Mirroring"
  - Unresolved Grief
  - Children never parented so never learned to parent
  - Boarding Schools
  - Coping: Unhealthy Behaviors

Long histories of subjugation, historical trauma, unresolved grief and the challenges of changing cultures, poor economics, and lack of opportunities are negative and destructive

Thank you Carolee Dodge for use of the slide
Cultural Considerations in Community Based Research

How May Historical Trauma Affect AIANs Use Of The Healthcare System?

- Example: distrust = avoid Western medicine
- What are specific examples related to cancer?
  - Cancer clinical trials (especially treatment trials)
  - Cancer genetic studies

2000 Census: Health Insurance

- Less than half of AIANs have private health insurance
- Most AIANs (as well as non-Natives) erroneously call IHS “health insurance”, but it is NOT
- AIANs self-report having health insurance on surveys based on error of calling IHS “health insurance” …
  - This is why the BRFSS and other surveys over-estimate AIANs insurance status
Cultural Considerations in Community Based Research

Tribal Outreach -- Cancer Information Web Pages

Native Cancer Information Resource Center and Learning Exchange
(Native C.I.R.C.L.E.)
http://www.mayo.edu/nativecircle/

The BEST source of Native-specific cancer information!

Tribal Outreach -- Cancer Information Web Pages

“The American Indian / Alaska Native Initiative on Cancer” (“Spirit of E.A.G.L.E.S.”) [U01 CA86098]

NEW: http://nativeamericanprograms.org

Cultural Considerations in Community Based Research; http://www.NatAmCancer.org
Examples of free downloads:
- Free downloads of slides from the 5 “Get on the Path to Health” Curricula (breast, cervix, colon, lung, prostate) [each has 6-7 modules]
- “Clinical Trials Education for Native Americans”
- “Native American Palliative Care” Curriculum
- “Native American Cancer Education for Survivors” (NACES) (quality of life interactive education)
- FACT Sheets: Native Elder Cancer Survivors, Tobacco

University of Michigan Health Systems
Marilyn Roubidoux, M.D. Associate Professor of Radiology
Mammogram Detective
Provider version: www.med.umich.edu/lrc/breastcancerdetective
Patient version:  www.med.umich.edu/lrc/bcdpatient

Mary Alice Trapp, Breast Health Bingo
(same website as provider version of detective)
Examples of Problems Experienced by Researchers / Public Health Professionals

- Assuming researchers’ and tribal perceptions of local problems are the same (e.g., migration genetic research relationship to some problem vs. diabetes)
- Working with the wrong Native “leader” or person
Cultural Considerations in Community Based Research

Examples of Problems Experienced by Researchers / Public Health Professionals

- Changing Tribal / Urban Program Administration
  - Most significant barrier to start-up and maintenance of AIAN cancer program is Administrative support
  - Kiss of death = Administrator who does not think cancer is important

Examples of Problems Experienced by Researchers / Public Health Professionals

- Throwing money at Native community to use as they wish, but give researcher the data (disrespectful)
- Researcher obtains letter of support / commitment from Native organization for grant application and then is not heard from again until time for competitive grant renewal
Cultural Considerations in Community Based Research

Examples of Problems Experienced by Researchers / Public Health Professionals

- High turnover within Native community project staff (usually related to insufficient budget)
- Researcher saying or implying, “I don’t care how you get it, but give me the data”
- Budget (volunteerism from Native community, but academicians receive salaries or buy-out for class loads)

Example of Project Approval Processes among IHS / Tribal / Urban Programs

- Local Tribal Committee for partnerships / decision-makers / leaders
- Tribal Resolutions / ordinance
- Tribal Research Committee/IRB
- IHS Area IRB
- IHS National IRB approvals

NOTE: IHS IRB is currently dysfunctional
What are criteria for community based participatory research (CBPR) or approach (CBPA)?

- Equal partner and decision-making role on every step / phase of the research project
- Planning the project
- Identifying the hypothesis
- Formulating the research plan
- Analyzing the data
- Writing the reports
- Disseminating and presenting project findings (publications, professional and community meetings)

What do Native Communities say they want?

- Control over the:
  - Planning (i.e., Health problems of priority to the community, not just to the researcher)
  - Methodology
  - Implementation
  - Evaluation
  - Quality data collection, storage and management
  - Reporting
  - Dissemination
Cultural Considerations in Community Based Research

**Cultural Perspectives of Research**

- Research results rarely shared with community
- Community not involved in designing the study protocols
- Distrust of researchers
- The benefits are limited to the researcher: Promotion, Publication, Patents and Wealth

- Exclusion of traditional medicines
- No improved access to necessary services
- Distrust of how research institutions will use the study findings, especially genetic studies
Examples of Barriers to CBPR from “Outside Partner’s Perspective

- Experience working with unstable or dysfunctional community groups
- Concerns about the community group’s skills to “get the job done” or to “get the job done right”
- Concerns about how the community will use the money

Examples of Barriers to CBPR from “Outside Partner’s Perspective

- Unable to give up (1) control; (2) power; and/or (3) money
- IRB / HIPAA and tribal project approval processes
- “Easier” for the “Outside Partner” to continue doing “things” as they’ve always been done
Potential Benefits of CBPR/A

- The project continues after funding is decreased / ceases
- The community learns skills that may help them implement other public health programs
- A strong, trusting partnership may be created that results in multiple subsequent projects

Potential Benefits

- The project outcomes are valid and reliable
- The community actively helps with dissemination because they feel ownership and pride in the project
- More likely to have increased availability of needed services in the community
Potential Drawbacks of CBPR / A

“Outside Partners” and community cannot come to a good working agreement for the project

“Outside Partners” and community have priorities that differ too much to make CBPR a reality

Cannot find a funder to support the project

Potential Drawbacks

Sometimes there are “Outside Partners” who you know just want to use you as a “token” or to demonstrate “diversity”

Asked to put the organization into their grant … even subcontract, then when the project is awarded, never see anyone from the organization again until it is time to write another letter of support.
Cultural Considerations in Community Based Research

Potential Drawbacks

- Many times the “Outside Partners” are interested in surveys, but not interventions.
  - Surveys = publications, promotions… [note: appropriate for graduate degrees]
  - Interventions = harder to do
- “ Outsiders” jump on the CBPR bandwagon and want to throw a project together because now there are CBPR-specific RFAs from NCI, CDC, ACS … violates NACR’s caveats

Examples of Unsuccessful Strategies

All implemented in specific AIAN settings
Outreach recruitment strategies -- Ineffective

- Telephone / mail
- Native male outreach workers for women’s programs
- Voter registration lists / Census lists
- News Stories / Releases in general newspapers
- Use of celebrities to deliver the messages

Education strategies -- Ineffective

- Education with partnership of Church
  - This may work eventually, just very limited / disappointing results from most Native communities
- Regular / generic Public Service Announcements (PSA) / videos
- Regular / generic radio or TV PSA
Cultural Considerations in Community Based Research

Breast Health Services -- Ineffective

- Mobile mammography in city within 50 miles of Native community
  - worked for urbans but not for reservation-based women
- Male health provider for women’s programs
- County health screening services
- General hospital / health care facility screening services

Examples of Successful Strategies

All implemented in specific AIAN settings
Successful Strategies for Breast and Cervical Cancer Screening Among American Indian and Alaska Native Women

Carlyn Orians, Paula Lantz, Edward Liebow, Jennie Joe, Linda Burhansstipanov, Julie Erb

Cancers detected and treated.

Interest in extending this model to meet other health care needs in their communities.
Cultural Considerations in Community Based Research

Key strengths of the program model

- The early detection program is comprehensive in nature
- The program does more than offer screening services
- Public education, tracking and follow-up, partnerships, and professional education equally important

Key strengths of the program model

- Comprehensive approach creates community orientation towards prevention
- The tribal programs are locally controlled
  - Greater self determination
  - Ability to shape program to meet needs of the community
  - Services delivered through trusted institutions and individuals
### Outreach Recruitment Strategies -- Effective

- **Multiple** strategies relevant to local AIAN community
- One-on-one recruitment
- Lay health advisors, Navigators (Native Sisters), Community Health Representatives
- Telephone calls or visits to remind woman of her appointments

### Outreach Recruitment Strategies -- Effective

- Native Cancer Survivors on staff as outreach workers
- Native American Navigators (Native Sisters)
- “Gifting” and incentives for completing screening appointment
- News Stories / Releases in Tribal or Urban newsletters or newspapers
Education Strategy - Effective

- Story Telling
- One-on-one delivery w/ culturally specific videos, fliers, brochures
- Native-specific PSAs / Videos
- Native-specific Radio or TV (e.g., Raven, Native American Calling, Alter-Native)
- Educational Activities need to include the sharing of healthy food
- Community programs, workshops presentations by local women

Breast Health Services -- Effective

- Mobile mammography within the Native community
- Female health provider
- Native-specific clinic screening
Cultural Considerations in Community Based Research

Story Telling

- Natural way for patients to explain and to understand (see side bar on NACES QOL Tree)

Story Telling

- Effective within outreach, education, support materials
- More effective with *local* AIAN person rather than a celebrity
**Native Sisters / Navigators**

- Understand IHS / Contract Health Service (CHS) budgetary limitations (created by Congress)

IHS is not now, never has been, never will be “health insurance”

- Use alternative ways to overcome IHS CHS

  - See “help and support” limb on the “Native American Cancer Education for Survivors” QOL Tree

---

**Increase Time Spent with Patient and Family to Discuss CT / Tx**

- Healthcare Institutions focus on business = providers allowed 15 minutes per patient visit

  - Alternative: Daniel Petereit, MD, Rapid City Regional Hospital, SD

    - Clinical Trial Explained in 2 sessions (one with family present)
    - 1 hour each session
    - ~30 AI patients recruited/retained in ATM genetic study!!!
Sub-Objective: Identify factors that increase the successfulness of navigation models (Native Sisters) in Indian Country.

Note: these slides are an excerpt of longer, comprehensive slides on NACR website

Native Sisters

Back Row: Brenda Seals, Lisa Harjo, Terri Rattler
Front Row: Denise Lindstrom, Audrey Marshall, Rose Lee
Characteristics of the Native Sisters

- Native
- Respected by the community (credibility in the community)
- Model healthy behaviors
- Passion for helping community members
- Education varies (service vs. grant)

Native Sisters’ 1994-1997 Functions
Excerpt of Challenges and Lessons Learned 1994-2006

Lessons Learned / Addressed

- Asking questions the wrong way (interrogative pronoun)
- Depending on others to consistently tell them what to do (leadership role so they are “in charge”)
- Giggling in embarrassment (one-on-one session with LB and inadvertent shaming of the elders)
Lessons Learned / Addressed

Culture behaviors and non-verbal behavior (as well as verbal ... “cancer” spirit)

Practicing how to say words. Role play using the words

Practicing explaining medical procedures

Learning how to fill out paperwork (different forms for every hospital/clinic)

Guessing at an answer rather than saying they’ll check and get back to the patient within the next day or two

“Surprise” visits role playing as community woman – harder to provide navigation with supervisor than with the community, but good experience for learning to think fast and get organized
Cultural Considerations in Community Based Research

### RECENT Challenges Sisters Address

- **Transportation**
  - Need to purchase supplemental auto insurance to cover both the Native Sister and the patient in case of an accident
  - Otherwise, the Sister’s personal auto insurance gets “hit” with the accident expenses
  - Ground travel costs … high cost of gasoline and Sisters may drive 100s of miles
  - Parking lot full – strategies to keep the patient comfortable inside the clinic until Sister finds parking space

### New Lessons

- Community-based vs. clinic vs. combination
- Native Sisters and cultural appropriateness
- Clinical settings and access to services