

Building Collective Agendas and Tools to Manage Research: Tribal Community Experiences

*Community-Campus Partnerships for Health
Conference Call Series on Building Community Capacity for Research
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National Congress of American Indians Policy Research Center

National Congress of American Indians

- Oldest, largest, and most representative national Indian organization serving the interests of tribal governments
- Established in 1944 as a representative congress of Indian tribal governments
- Serves as a forum for consensus-based policymaking



National Congress of American Indians

- Addresses the broad spectrum of issues that tribal governments are concerned with: from cultural preservation and natural resources and from education to economic development
- Aspects of our work: advocacy, legal analysis, policy development, public/media education and outreach, policy research, and tribal capacity building



“Outsiders have researched us to death, and the research doesn’t even benefit us.”

*-Former Councilman Eddie Tullis
Poarch Band of Creek Indians*



“Data is political.”

-Dr. Stephen Cornell

*Director, Udall Center for Studies in Public Policy,
University of Arizona*



“Tribes need data to support their own self-determined agendas.”

-W. Ron Allen

Chairman, Jamestown S’Klallam Tribe



NCAI Policy Research Center

- Established in 2003 as a national tribal policy research center that would focus solely on issues facing tribal communities
- Forum for forward-thinking, deliberate, proactive Indian policy discussions and the development of policy scenarios



PRC Funders

- Administration for Native Americans, U.S. Department of Health & Human Services
- Annie E. Casey Foundation
- Bill and Melinda Gates Foundation
- Ford Foundation
- National Institute of Justice, U.S. Department of Justice
- NeighborWorks America
- Oneida Nation of Wisconsin
- Shakopee Mdewakanton Sioux Community
- Stewart Title Co.
- W.K. Kellogg Foundation



PRC Vision

*supporting Indian Country in
shaping its own future*



PRC Values

- Research in service to community
- Direct implications for communities and improving their well-being
- Community-driven agenda and all aspects of the work
- Honor community and cultural contributions to the work



PRC Values

- Partnership with communities and other organizations
- Respect tribal sovereignty and ownership of data
- Indigenous knowledge is as valid as academic knowledge
- Research should build community capacity



Core Buckets of Work

- Clearinghouse
- Research Support
- Capacity Building
- Think Tank



PRC Work

- Making data available and translating research into practice
 - Web-based data clearinghouse of publicly available
 - Annual Tribal Leader/Scholar Forum
 - Topical convenings
 - Research products



PRC Work

- Research support
 - Identify research questions prioritized by tribal leadership
 - Inform development of appropriate research plans
 - Identify/adapt/create appropriate measures
 - Data analysis



PRC Work

- Tribal capacity building
 - Information about tribal options for regulating research
 - Data collection, program evaluation, and research curriculum
 - Research tools
 - Technical assistance
 - Identify promoters and inhibitors of effective community-based participatory research (CBPR)



PRC Work

- Think tank
 - Forecast emerging policy issues
 - Convene critical stakeholders to “have the conversations that no one else will”
 - Develop policy scenarios and assess impact of various policy options



Building Agendas for Research

COMMUNITIES  OF PRACTICE

- Communities of Practice Program
- Networks diverse stakeholders around key issues to Indian Country to build collective research and policy agendas
- Serves as an informal forum to discuss research and policy priorities, share input on current projects
- The collective agenda helps strategically focus resources (financial, academic, etc.) to meet Indian Country's priorities



Tribal Leader/ Scholar Forum



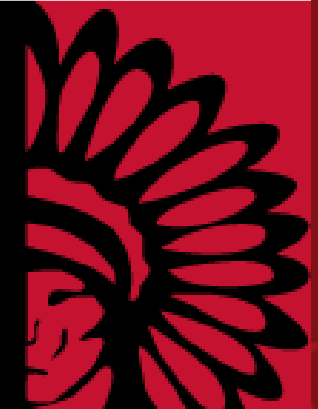
- Selected researchers share their work with tribal leaders and other participants at our Mid-Year session
- Tribal policymakers offer feedback to researchers about the impact, and potential next steps of their work
- Special emphasis on the practical, real-life implications of research
- This year's focus: law enforcement/public safety, health care, natural resources, energy development, strategies for strengthening tribal governance



5th Tribal Leader/Scholar Annual Forum



June 22, 2010



Presented by the National Congress of American Indians Policy Research Center



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Questions?



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Tools for Communities to Manage Research



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Research that Benefits Native People

A GUIDE FOR TRIBAL LEADERS

FOUNDATIONS OF RESEARCH:
AN INDIGENOUS PERSPECTIVE

UNDERSTANDING EVALUATION

MANAGING THE DESIGNING
AND PLANNING OF RESEARCH

CONDUCTING RESEARCH IN
PARTNERSHIP WITH OTHERS

USING ETHICS AS A GUIDE
FOR MANAGING RESEARCH

MODULE 1

Foundations of Research: An Indigenous Perspective



Research Curriculum

- Foundations of Research: An Indigenous Perspective
 - Introduction to how tribal values relate to research; these are emphasized throughout the curriculum.
 - Introduction to the context and situations in which a tribal leader may need a working knowledge of research and related issues.



Module 1 available at:

<http://www.ncaiprc.org/research-curriculum-guide>

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Research Curriculum

- Managing The Designing And Planning Of Research
 - Designing a research study
 - Developing a research plan
- Using Ethics As A Guide For Managing Research
 - Identify, understand, and apply basic ethical considerations related to conducting research



Research Curriculum

- Conducting Research With Others
 - How to choose, evaluate a research partner
 - Tribal research policy: Institutional Review Boards (IRBs), research agreements, etc.
 - Skills for being an effective partner
- Understanding Evaluation
 - Designing, implementing a program evaluation
 - Culturally competent evaluation techniques for tribal communities



Research Regulation Papers

- Policy and Practice Considerations
- Guide to Reviewing Research Studies
- Tribally-specific considerations related to research
- Could be useful to other communities also re: collective decision making, regulation of research



Papers available at:

<http://www.ncaiprc.org/research-regulation-papers>

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Ethical Values

- Belmont Report
 - Federal ethics guidelines for research
 - Respect for persons, justice, beneficence
- Native Ethical Frameworks
 - Akwesasne Task Force on the Environment
 - *Skennen* (peace/justice), *Kariwiiio* (good word), *Kasastensera* (strength/power)



Legal Ways to Regulate Research

- Legal Contracts with Researchers
 - Explicitly sets the terms for research conduct
 - May require substantial time and resources to develop
 - Consider using template contract
 - Models:
 - Indigenous Peoples Council on Biocolonialism
<http://www.ipcb.org/publications/policy/index.html>
 - Canadian Aboriginal AIDS Network
[http://depts.washington.edu/ccph/pdf_files/Principles of Research Collaboration Template.doc.pdf](http://depts.washington.edu/ccph/pdf_files/Principles_of_Research_Collaboration_Template.doc.pdf)



Community Review Board Models

- Institutional Review Board (IRB)
- Community Advisory Board (CAB)
- Existing community committee
- Contracting with outside IRBs
- Consortium Review Board



IRB Training Resources

- Collaborative IRB Training Initiative (CITI)
- Family Health International curriculum
- National Cancer Institute
- Office of Human Research Protection
- NCAI Research Curriculum

[http://www.ihs.gov/MedicalPrograms/Research/irb
Train.cfm](http://www.ihs.gov/MedicalPrograms/Research/irbTrain.cfm)



Research Review Checklist

- Tool for community review of research
- All stages of a study
 - Proposal
 - Informed consent forms
 - Ongoing reports
 - Publications and products
- Community, individual risks and benefits
- Narrative for checklist - paper



Research for Change

- Conducted by NCAI PRC, University of Washington, University of New Mexico
- Study of promoters of effective CBPR
- Native and non-Native communities
- Governance a key variable
- Quantitative and qualitative methods
- CBPR Community of Practice



Conclusion: Lessons Learned

- Communities (Native and non-Native) can use collective power to regulate research
 - Research review processes
 - Legal contracts/enforcement
- Education for building capacity
 - Defining research and other academic terms
 - Glossary
 - Confidence to engage with researchers
 - Authority to regulate research



Questions?



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