Hello

Building Research Capacity through Institutional Review Boards (IRB)

Anita Frederick
Tribal Nations Research Group
Establish March 2013
Tribally Chartered 501c3
Overview

- Introduction to IRB/RRB
- Overview of Tribal Nations Research Group
  - The importance of data ownership in protecting tribes;
  - TMBCI Research Review Board
- Starting an IRB/RRB in your community
- Challenges
- Funding
- Community Initiatives
When you think about Institutional/Research Review Boards, what is the first thing that comes to mind?

- Regulation
- Work
- Human Subjects Research
- College or University
- Professors/Students
- Problem Solving
Types of Institutional/Research Review Boards in Tribal Communities

- Tribal Nation IRB
- Tribal College IRB
- IHS IRB
- Tribally Focused Organization IRB
- What is the role of an IRB
  - Typically it is for research oversight;
  - Ensure protection of Tribal Citizens;
  - Ensure research is conducted in an ethical manner that is respectful of place.
➢ A little bit about Tribal Nations Research Group?
➢ Established-March 2012
➢ Received 501c3 status in January 2014
"To improve the quality of life for all tribal members through culturally-competent, custom-fit research"
Purpose

• Purpose
  • Develop a statutory process to review, govern, maintain, and house all research, collection, database, video collection, or publication undertaken within the Turtle Mountain Community.

• Relationship with Turtle Mountain Band of Chippewa Indians (TMBCI)
  • Establish a formalized process to protect the people, culture, and natural resources of TMBCI.
    • Research Review Board
  • Establish and manage the TMBCI Research Department.
    • Research Agenda
    • Research Catalog
  • Data center/repository that will be the official reporting entity for the TMBCI and subsidiaries.
  • Inform and educate the TMBCI community about the research process, data use, data ownership, and distribute updates about research.
Staff

• Anita Frederick  
  • President
• Erin Garrison  
  • Research Liason
• Larretta Hall (April 2018)  
  • Grants and Project Management
• Lucinda LaRocque  
  • Business Office
• Christa Monette  
  • Data VISTA
• Vacant  
  • Community Engagement VISTA

Senior Associates/Board of Directors

• Dr. Carol Davis, EdD
• Dr. Gerald “Carty” Monette, EdD
• Stanley LaFountain
• Debbie LaVallie
• Vincent Grant

Associates

http://www.tnrg.org/
<table>
<thead>
<tr>
<th>Community Health Coalition</th>
<th>Food Sovereignty Coalition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geri Ann Azure, PhD</td>
<td>Debbie Poitra</td>
</tr>
<tr>
<td>Melanie Nadeau, PhD</td>
<td>Jessica Ferris</td>
</tr>
<tr>
<td>Tami Jollie-Trottier, PhD</td>
<td>Mark Hamley</td>
</tr>
<tr>
<td>Andrea Laverdure, EdD</td>
<td>Betty Hamley</td>
</tr>
<tr>
<td>Denise Lajimordiere, PhD</td>
<td>Jackie Giron</td>
</tr>
<tr>
<td>Ben Poitra, PhD</td>
<td>Duran Parisien</td>
</tr>
<tr>
<td>Amber Mathern, Ed D</td>
<td>Rhea DeCoteau</td>
</tr>
<tr>
<td>Shane Martin, Ed D</td>
<td></td>
</tr>
<tr>
<td>David Bake Azure</td>
<td></td>
</tr>
<tr>
<td>IHS Representative</td>
<td></td>
</tr>
<tr>
<td>Francis Allard-Abbot</td>
<td></td>
</tr>
<tr>
<td>(Cultural Rep)</td>
<td></td>
</tr>
<tr>
<td>Laurie K Davis</td>
<td></td>
</tr>
<tr>
<td>(Community Member)</td>
<td></td>
</tr>
<tr>
<td>Stephanie Jay</td>
<td></td>
</tr>
<tr>
<td>(Community Member)</td>
<td></td>
</tr>
<tr>
<td>Blaine Malaterre</td>
<td></td>
</tr>
<tr>
<td>Jackie Giron</td>
<td></td>
</tr>
<tr>
<td>Stephanie Jay</td>
<td></td>
</tr>
<tr>
<td>Shanon Marion</td>
<td></td>
</tr>
<tr>
<td>Laurie K. Davis</td>
<td></td>
</tr>
<tr>
<td>Joe Eltobgi</td>
<td></td>
</tr>
<tr>
<td>Jona Peltier</td>
<td></td>
</tr>
<tr>
<td>Denise Marcellais</td>
<td></td>
</tr>
<tr>
<td>Maxine Desjarlais</td>
<td></td>
</tr>
<tr>
<td>Glenn Longie</td>
<td></td>
</tr>
<tr>
<td>Beverly Davis</td>
<td></td>
</tr>
<tr>
<td>Ashley Parisien</td>
<td></td>
</tr>
<tr>
<td>2 Tribal Council Members</td>
<td></td>
</tr>
</tbody>
</table>
Partnerships

- Turtle Mountain Band of Chippewa
  - Tribal Government
  - Pathways to Prosperity
  - Many Tribal Programs
- Collaborative Research Center for American Indian Health & Tribal Partners
  - Sisseton Wahpeton Oyate
  - Pine Ridge
  - Rosebud
  - Fond du Lac
- BUSH Foundation
- National Science Foundation
- First Nations Development Institute
- ND Department of Health & Human Services
- North Dakota State University
- American Indian Public Health Resource Center
WHY

- TMBCI Tribal Leaders had no control of the research being conducted on the TMBCI.
- Students have difficulty finding articles or data to support their efforts in writing papers, thesis, or dissertations.
- Researchers have difficulty finding data to support their research.
- Research results were not utilized or communicated to the community.
Storage of data and data collection systems is neither coordinated nor comprehensive.

Tribal leaders do not have the data they need to make decisions or do strategic planning.

Grant writers do not have data needed to prepare proposals.

Health Care Administrators need to know what essential services the community needs.

Program Directors do not have the data they need to make decisions about their programs or services needed within our community.

Coordinate Infrastructure

Economic Development

Identify community needs/issues/how to address the issues
PHASE 1

TNRG & TMBCI partners

- Research Review Board
- Catalogue past research
- Collect list of secondary data sources
- Track Research
- Research Results
- Develop a research data base-results, researcher, funding
- Analyze secondary data information
- Data Sharing/Use agreements
- Understanding Prior Research-develop a research agenda
- Find what is good, know what we need to collect
How

Phase 2

Evaluate:
- Technology
- Policy
- Communication
- Resources

Data Warehouse

Programs/Services of TMBCI

Tribal Enterprise

Government Agencies

Private Independent Business

Mine Data

Find Patterns

Tribal Members-Community

Tribal Leadership

Program Managers
Results

- Data
  - Data sovereignty
  - Data protection
- Research is not always academic in nature
- Educated and informed community
- Increase in communication across the community, stakeholders, and constituents
- Stronger decision making
- Improved planning
- Targeted resources
- Overall community improvement.
- Respect for research and data needs
Thoughts

Thoughts on
Institutional Review Boards
Considerations

What to consider

- How is your relationship with the following:
  - Tribal Government
  - Community
  - Academic Community
- How much effort can you give to doing this process?
- Are you willing to commit human and financial resources to managing a RRB for all of Standing Rock
- We believe it is all or nothing
- Will be surprised that most research is not conducted with academic partners
  - Evaluations
  - What the world thinks is exempt, is usually not exempt in a tribal community

- Where will there be the most stability?
- Where will there be the most communication with the community?
- One of the most important aspects of a Tribal Research Review Board is informing the community about research!
- Opportunity to build our research capacity as Tribes!
  - Now is the time for us to do our own research!
Cost
- Annual Salary of ½ time RRB Administrator $25,000
- Annual Salary of ¼ time Chair, $17,000
- Annual Software Agreement $3,000
- Storage $500
- Meals for RRB members $600
- Training for RRB members $4000
- CITI Certification varies

How do we pay for everything?
- Grant from the Collaborative Research Center for American Indian Health – Sanford Research, Sioux Falls ND (Ends July 31, 2018)
- Additional funding for data center
  - Bush Foundation
  - Contracts
  - Evaluation
  - Research Grants
  - Small grants
Membership
- All RRB members are Enrolled TMBCI Citizens
- Consists of 7 voting members
  - 2 scientific
  - 2 non-scientific
  - 1 cultural
  - 1 member at large
  - Use consultants as needed
- RRB Chair
- RRB Administrator
- Primary Reviewer System

- Regular meeting once a month on the second Wednesday of the month
- Use Purchased Software (mentor) to manage protocol submissions, correspondence between PI and RRB Chair/Administrator
- All Documents, Publications, Data, etc is maintained in the software.
- Streamlined process-No missed submissions
- No documents going back/forth
- Saved on printing and storage cost
IRB Process

Review Process

- RRB Chair completes a pre-review of all new protocols, reviews for:
  - Complete Application
  - CITI Documentation
  - Informed Consent

- Reviewer Checklist
  - Informed Consent
  - Protocol
The reviewers keep the following questions in mind when reviewing protocols:

- Is there a similar study that has been done in the past?
- Does the research address an issue that is prevalent within our community?
- Does the research “Build Capacity” within our community?
- Who are the partners, what is our communities public benefit?
- Is the researcher connecting with a partner?
Challenges

- Staffing
- Maintaining relationship with Tribal Government
  - Maintain ourselves as an organization
  - Need to continue to prove ourselves as an asset to the Tribe
    - Work hard, timely, and provide a service
    - Engage Tribal Members who want to be involved (these are usually leaders in your community)
  - Volunteering
  - Mentoring
- Finances
  - Hard to maintain—plan for the future
- Community Naysayers
Survival

- Large Organizations
- Establishing a Niche? What makes our organization different, innovation!
- Researchers
  - Often don’t want to adjust study
  - Don’t want to include partners in publications
  - COMMON Rule
  - Report it in Black and White, Layman's Terms
- Data Analysis
Projects

- Community Health Assessment
- Food Sovereignty Assessment
- Workforce Assessment
- Demographic Survey
- Community Dashboard
- Evaluation Project
- OPOID Research
- STEM Research
Thank You
To learn more about TNRG
Please visit our website:

http://www.tnrg.org

PHONE: Anita Frederick-701-477-5526