



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



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



TNRG Mission



"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/>



Community



RRB

- Geri Ann Azure, PhD
- Melanie Nadeau, PhD
- Tami Jollie-Trottier, PhD
- Andrea Laverdure, EdD
- Denise Lajimordiere, PhD
- Ben Poitra, PhD
- Amber Mathern, Ed D
- Shane Martin, Ed D
- David Bake Azure
 - IHS Representative
- Francis Allard-Abbot
 - (Cultural Rep)
- Laurie K Davis
 - (Community Member)
- Stephanie Jay
 - (Community Member)

Community Health Coalition

- Blaine Malaterre
- Jackie Giron
- Stephanie Jay
- Shanon Marion
- Laurie K. Davis
- Joe Eltobgi
- Jona Peltier
- Denise Marcellais
- Maxine Desjarlais
- Glenn Longie
- Beverly Davis
- Ashley Parisien
- 2 Tribal Council Members

Food Sovereignty Coalition

- Debbie Poitra
- Jessica Ferris
- Mark Hamley
- Betty Hamley
- Jackie Giron
- Duran Parisien
- Rhea DeCoteau



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



Capacity Building

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



Capacity Building

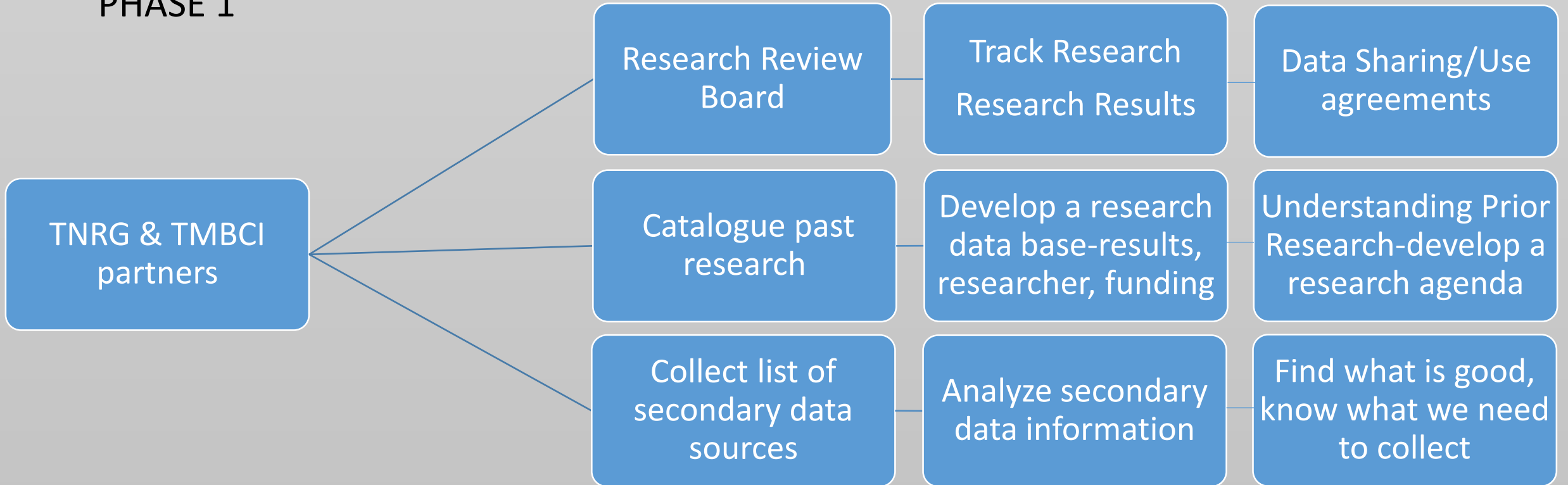
- Storage of data and data collection systems is neither coordinated nor comprehensive.
- Tribal leaders do not have the data they need to make decisions or do strategic planning.
- Grant writers do not have data needed to prepare proposals.
- Health Care Administrators need to know what essential services 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



How

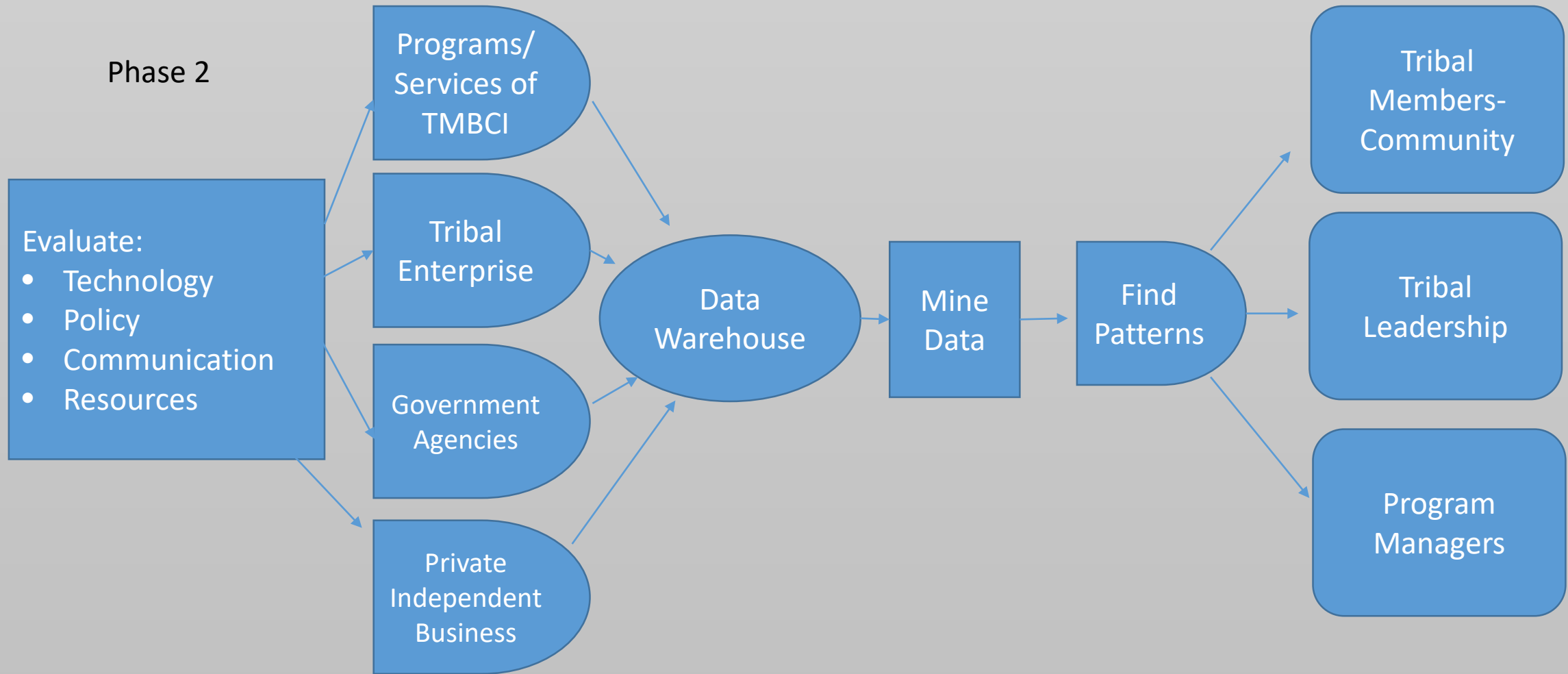


PHASE 1





How





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



IRB Process



- 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



Questions



Thank You
To learn more about TNRG
Please visit our website:

<http://www.tnrg.org>

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