Tribal Research Infrastructure Building Update

Emily White Hat, JD
CRCAIH Tribal Partners

• Fond du Lac Band of Lake Superior Chippewa
  – Cody Bassett, BASc
• Oglala Sioux Tribe
  – Elizabeth Belt, BS
• Sisseton Wahpeton Oyate
  – Dawn Eagle, MA
• Turtle Mountain Band of Chippewa Indians
  – Anita Frederick, MS
• Candeska Cikana Community College/Spirit Lake Tribe
  – Bonita Morin, MSW
Tribal Partner Update

Presented by Cody Bassett
Research Specialist
1995
- Fond du Lac Human Services establishes an Institutional Review Board
- Functioned from this time forward and allowed for a voice in research

2014
- January - Work began on new policies and procedures
- July - Policies and procedures approved
- August - Board member selection
- December - First meeting
OPIOID USE AND TREATMENT HISTORY
INTERVIEW

- The opiate crisis
  - Prescription drug abuse is a “public health epidemic” -CDC
  - Leading cause of accidental deaths in the United States

- Concerns over opioid use within the community
  - Community concerns
  - Overdoses
Purpose was to learn more about the opiate using community as well as identify any possible patterns

Collected data January 2015

Community experts identified potential participants

62 participants

Interview
- 56-item inventory
- Questions regarding:
  - Prescription Drugs
  - Methadone
  - Treatment
  - Community

Come to the poster session to learn more!
**FUTURE GOALS**

- Complete current projects
- Plan follow-ups
- Continue work on opiate crisis
- Begin planning for 2016 community needs assessment
Oglala Sioux Tribe – Updates

Elizabeth Belt, B.S.
Health Research Coordinator
OSTRRB Coordinator

This presentation is supported by the National Institute on Minority Health and Health Disparities of the National Institute of Health under Award Number u54MD008164 (PI – Elliott)
Oglala Sioux Tribe

- 8th largest reservation
- Southwest corner South Dakota
- 56,000 enrolled members
Highlights

• OSTRRB Submissions website

• Community Research Conference

• OST Research Agenda
OSTRRRB Submissions

• Electronic submission

• Current host OSTRRB Forms

• Potential 1st tribal nations to use electronic submission
OSTRRB Submissions

• Initial Review
• Amendments
• Annual/Continuation Review
• Final Report
• Data Return Report
• Publications
OSTRBB Submissions

• Institution Id – oglala

• Need to create login within 24 hours or ask for information to be resent

• It is okay to add research coordinators to your protocols
Community Research Conference

• “No Longer Dreaming – Your Role in Native American Research”

• May 7, 2015

• SuAnne Big Crow Boys & Girls Club, Pine Ridge, South Dakota
Community Research Conference

• 70 attendees
  – 52 were tribal members

• Conference Assistant – Lyndon Brown

• Working Group – Amanda Carlow, Bernadette Denny
Community Research Conference

• OLC – KOLC

• KILI – Local Radio Station

• More Community Involvement
Research Agenda

• Electronic Library

• Surveys

• Talking Groups

• Community engagement

- Non-Health Research: 28%
- Cardiovascular Health: 14%
- Chronic Disease: 13%
- Cancer: 4%
- Children’s Health: 7%
- Genetics: 6%
- Other Health Topics: 6%
- Diet & Physical Activity: 3%
- Substance Use/Abuse: 6%
- Women's Health: 5%
- Mental Health: 5%
- Infectious Disease: 3%

n = 263
Electronic Library – # Initial Protocols Reviewed per year since Inception

- Number of initial protocols reviewed each year from 2007 to 2013.
- The highest number of protocols was reviewed in 2010.
- The lowest number of protocols was reviewed in 2007.
- Total number of protocols reviewed since inception: 187.

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Surveys – Youth

- Alcohol/Drinking 175
- Diabetes 113
- Suicide 96
- Drugs 91
- Obesity/Weight 80
- Asthma 44
- STDs 39
- Oral Health 23
- Teen Pregnancy 23
- Cancer 20
Surveys – Adults

- Diabetes 291
- Alcohol/Drinking 199
- Cancer (unspecified) 71
- Heart Disease 70
- Obesity/Weight 57
- Drugs 54
- High Blood Pressure 31
- STDs 26
- Smoking/Tobacco 25
- Cirrhosis/Liver 24
Surveys – Elders

- Diabetes 220
- Cancer (unspecified) 151
- Heart Disease 108
- Alcohol/Drinking 38
- High Blood Pressure 24
- Abuse 20
- Vision 17
- Arthritis 14
- Lung Problems/cancer 14
- Poor Healthcare 12
Talking Groups

- Obesity
- Cancer
- Children’s teeth/dental
- Suicide
- Diabetes
- Drug & Alcohol/Drug Abuse
- HIV
- Mental Health
- Environment/Housing
Community Engagement

• Top #1’s
  – Substance Use/Abuse
  – Cancer
  – Mental Health

• Top #2’s
  – Diet & Physical Activity
  – Mental Health
  – Substance Use/Abuse
  – Cancer
Community Engagement

• Top # 3’s
  – Diet & Physical Activity
  – Substance Use/Abuse
  – Children’s Health

• Top #4’s
  – Diet & Physical Activity
  – Children’s Health
  – Substance Use/Abuse
Ongoing/Future Projects

• Continue to work/update electronic library
• Furthering the research agenda
• Building OSTRRB’s website
Contact Information

Elizabeth Belt

Health Research Coordinator – OST Health Administration – ebelt@oglala.org

OSTRRB Coordinator – ostrrb@gmail.com

PO Box 5011, Pine Ridge, SD 57770
(605) 867-1704 ext. 212
SISSETON-WAHPETON OYATE TRIBAL INFRASTRUCTURE BUILDING UPDATE

DAWN EAGLE

JUNE 10, 2015
• Historical context of research
• Today, tribes asserting their Tribal Sovereignty

--MOTION ESTABLISHED SWO LRRB, OCT. 2013
--RESOLUTION, JUNE 2014 TRIBAL EDUCATION DEPARTMENT SPEARHEADED EFFORT-CRCAIH
--IMPLEMENTED REVIEW BOARD
--RESEARCH CODE PROCESS
SEVEN DISTRICTS, COMMITTEE(S), LEGAL, DCA, RESERVATION–WIDE, TRIBAL COUNCIL
Major accomplishments of the partnership was the development and implementation of the LRRB and finalizing process, completion of the paper submission and accompanying documents of all research applications.

GOALS:
1. TO BE ABLE TO GO LIVE FROM PAPER TO ELECTRONIC SUBMISSION
2. COMPLETE P&P
• Transition from Tribal Council, Human Services Board, Local Research Review Board (LRRB)
• Website development (www.swnsn.gov/?p=656)
• Data management and community outreach (ongoing)
• Weighing the pros and cons of research
• Final comments
Turtle Mountain Band of Chippewa Indians & Tribal Nations Research Group

Presented by:
Anita Frederick
History Research Infrastructure Building at TMBCI

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feb-15</td>
<td>TNRG Board met to discuss organizing TNRG-A Group focused on research at TMBCI.</td>
</tr>
<tr>
<td>Mar-13</td>
<td>TERO License issued to TNRG as a Research &amp; Development Non-Profit.</td>
</tr>
<tr>
<td>May-13</td>
<td>TNRG/TNBCI received CRCAIH Award.</td>
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<tr>
<td>Aug-13</td>
<td>1st Draft Research Protection Act completed</td>
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<tr>
<td>Nov-13</td>
<td>Purchase AXIOM Research Software</td>
</tr>
<tr>
<td>Mar-14</td>
<td>TMBCI/TNRG adopted resolution to place TMBCI RPA out for 30 day comment period.</td>
</tr>
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<td>Apr-14</td>
<td>Accepted Partnership with AIPHRC</td>
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<td>May-15</td>
<td>Begin Developing draft RRB policy &amp; Procedures</td>
</tr>
<tr>
<td>Jul-14</td>
<td>TNRG Submitted Application for 501c3 status</td>
</tr>
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<td>Aug-14</td>
<td>Formal Application process placed on website</td>
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<td>Sep-14</td>
<td>Scheduled 1st official meeting of the TMBCI Research Review Board</td>
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<td>Oct-14</td>
<td>Received Bush Foundation Community Innovation Grant</td>
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<td>Nov-14</td>
<td>Began bringing together TMBCI associate members</td>
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<tr>
<td>Dec-14</td>
<td>TNRG received notification of 501c3 determination</td>
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<td>Jan-15</td>
<td>TM Health Fair</td>
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<td>Received P2P award to establish Data Center and to conduct community surveys.</td>
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<td>Research management software set-up</td>
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<td>Hired new TMBCI Research Liaison-Mr. Harvey LaRocque!</td>
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<td>Jun-15</td>
<td>TNRC met in Grand Forks to prepare presentation to TMBCI Council.</td>
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<td>Apr-13</td>
<td>TNRC meeting with Tribal Council</td>
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<td>TMBCI adopted resolution establishing TNRC</td>
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<td>Aug-13</td>
<td>TNRG Hires CEO</td>
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How has CRCAI H helped

• Providing support
  • Someone to discuss an issue with;
  • Someone to toss ideas at;
  • Someone to discuss our frustrations with;
• Providing guidance, knowledge and expertise
  • Regulatory Core
  • Methodology Core
  • Community Innovation and Engagement Core
  • Administrative Core
Future Goals

- Secure additional funding
  - Sustainability
  - Support Research
- Have the data center established and in use by community
- Work with TMBCI Tribal Government to implement information management software
- Establish a committed and active Community Advisory Board
To learn more about TNRG and TMBCI
Please visit our website:

http://www.tribalnationsresearchgroup.org

QUESTIONS
RESEARCH

- What has been done in the past?
- What is being done currently?
- What we propose to do in the future...
1. The Spirit Lake Tribal Council reviewed and approved proposed research. 
   - Research conducted on various types of topics, many of which included human subjects research.

2. The Spirit Lake Tribe Research Infrastructure. 
   - Sanford Health Grant 2 year project awarded in August 2014 to the college.

   - Tribal Resolution A05-15-074 & BEYOND
Research Review Board [RRB]?

• The body responsible for review and approval of all research studies on behalf of the Spirit Lake Tribe. A Tribally driven board with authority over all research.

Purpose of an RRB?

• Protection of Human Subjects, Animals, & Cultural resources in our tribal community.
• Ensure that research is conducted ethically and legally.
• Benefits vs. risks to our tribal community.

Mission of the RRB?

• To positively contribute to educational and scholarly activities within the community THAT WILL BENEFIT THE TRIBE IN GENERAL.
Maximizing potential benefit for our community

Minimize potential risk

- Understand the protocol

Ensure compliance of all regulations governing research

Ensure consent process fully informs volunteers

Assist in promoting good research that will benefit our community
RESEARCH
Questions
Networking/Poster Session

Hammons Room