

# Working with American Indian communities to utilize and improve data for health research

Jessica Hanson, PhD  
Wyatt Pickner, BA, BS  
Susan Puumala, PhD



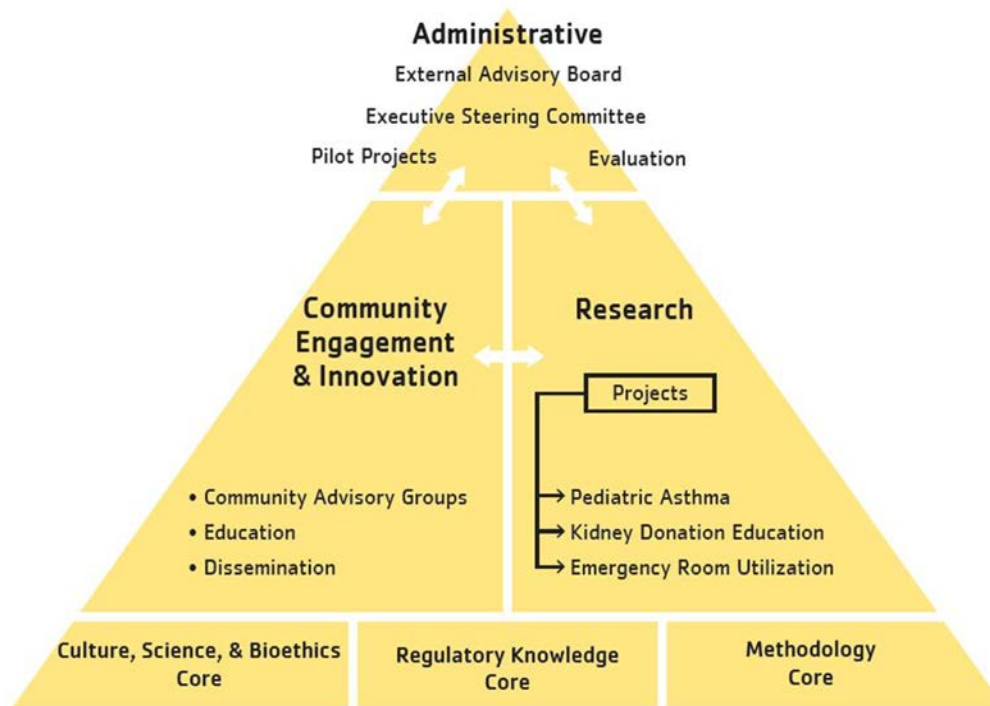
# Presentation Outline

- Collaborative Research Center for American Indian Health
  - Overview
  - Methodology Core
- Community input and utilization of tribal data for program development
- Access and utilization of local data
- Regional and national data for health indicator measurement



# Collaborative Research Center for American Indian Health (CRCAIH)

Building American Indian Health Research through Transdisciplinary Collaboration

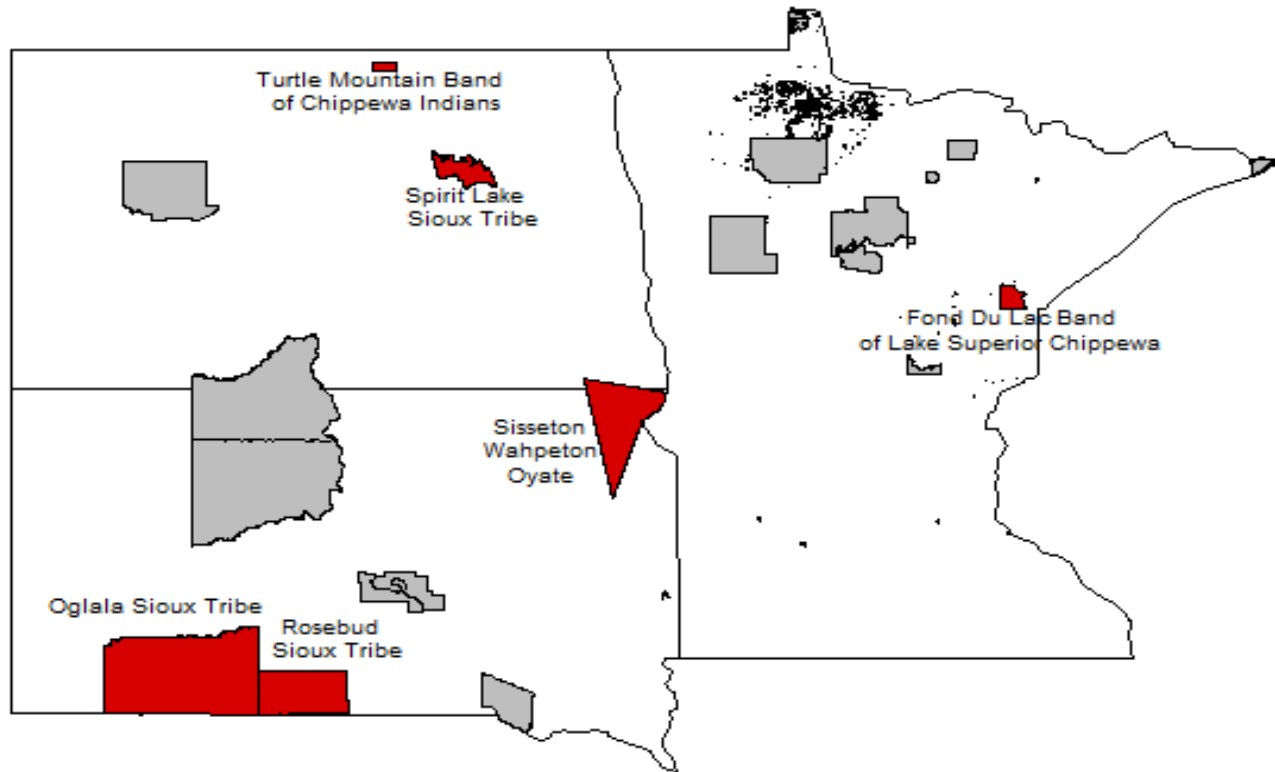


# Core Values

- **Transdisciplinary:** Create partnerships with Tribal communities, researchers, health care entities previously working in isolation to improve the human condition and raise awareness for health disparities.
- **Sustainability:** Build a foundation for infrastructure with Tribal communities to sustain research and advance policy in the region to improve health.
- **Tribal Sovereignty:** Work with Tribal partners to develop research agendas and research infrastructure to address their unique health priorities and overall vision of the tribe.

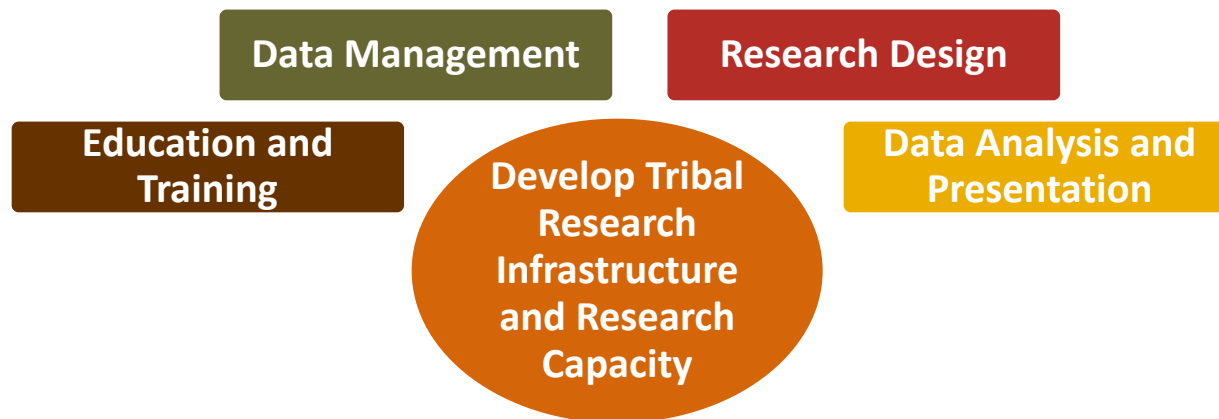


# Region



# CRCAIH Methodology Core

- Support for research projects involving American Indian health
  - Study planning and design
  - Data analysis
  - Interpretation and presentation
- Assist our tribal partners in building their research infrastructure
  - Research data storage and data management plans
  - Training in research methods and software for storage and analysis



# CRCAIH Partners

## Tribal Partners

- Fond du Lac Band of Lake Superior Chippewa
- Oglala Sioux Tribe
- Rosebud Sioux Tribe
- Sisseton Wahpeton Oyate
- Cankdeska Cikana Community College/Spirit Lake Nation
- Turtle Mountain Band of Chippewa Indians/Tribal Nations Research Group

## Organizations

- American Indian Cancer Foundation
- Great Lakes Inter-Tribal Epidemiology Center
- Great Plains Tribal Chairmen's Health Board
- Missouri Breaks Industries Research, Inc.
- National Congress of American Indians Policy Research Center

## Academic Institutions

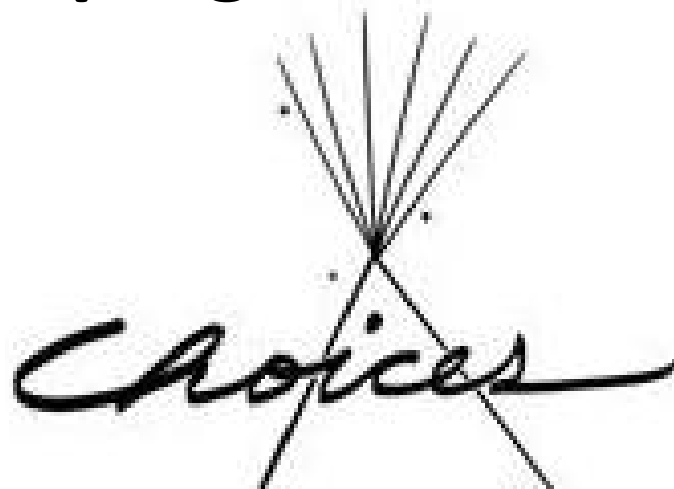
- Sanford Research
- North Dakota State University
- South Dakota State University
- Turtle Mountain Community College
- United Tribes Technical College
- University of Colorado Denver
- Univ. of New Mexico Institute for Indigenous Knowledge & Development
- University of North Dakota
- University of South Dakota
- University of Washington Indigenous Wellness Research Institute

## Health Care Entities

- Children's Hospitals and Clinics of MN
- Rapid City Regional
- Sanford Health



# Community input and utilization of tribal data for program development



Jessica D. Hanson, PhD

Associate Scientist, Sanford Research

Assistant Professor, Department of OB/Gyn, Sanford School of Medicine

May 19, 2016



# Objectives of Today's Presentation

- Describe how existing tribal research data was utilized for program development.
- Discuss gathering community input to assess the feasibility of an evidence-based program.
- Provide preliminary data on the successful implementation of prevention program with one American Indian community.

# Alcohol-exposed pregnancy (AEP)

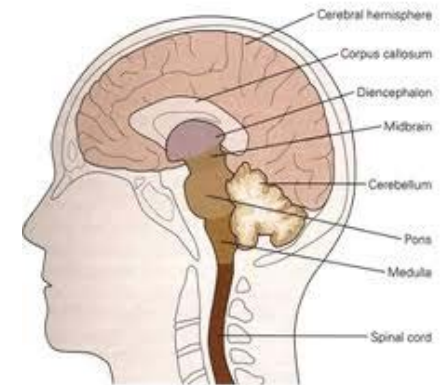
- Negative health risks associated with alcohol consumption during pregnancy represent a leading preventable cause of disabilities in the United States (SAMHSA, 2014).
- Fetal alcohol spectrum disorders (FASD) is the continuum of outcomes in individuals prenatally exposed to alcohol.
  - Includes a diagnosis of fetal alcohol syndrome.

- Timing and pattern of drinking impacts the range of effects.
- Heavier drinking, especially during the 1<sup>st</sup> trimester, is associated with facial features of FAS.

Sources:

Centers for Disease Control and Prevention (2004)

Russell M, et al (1991)



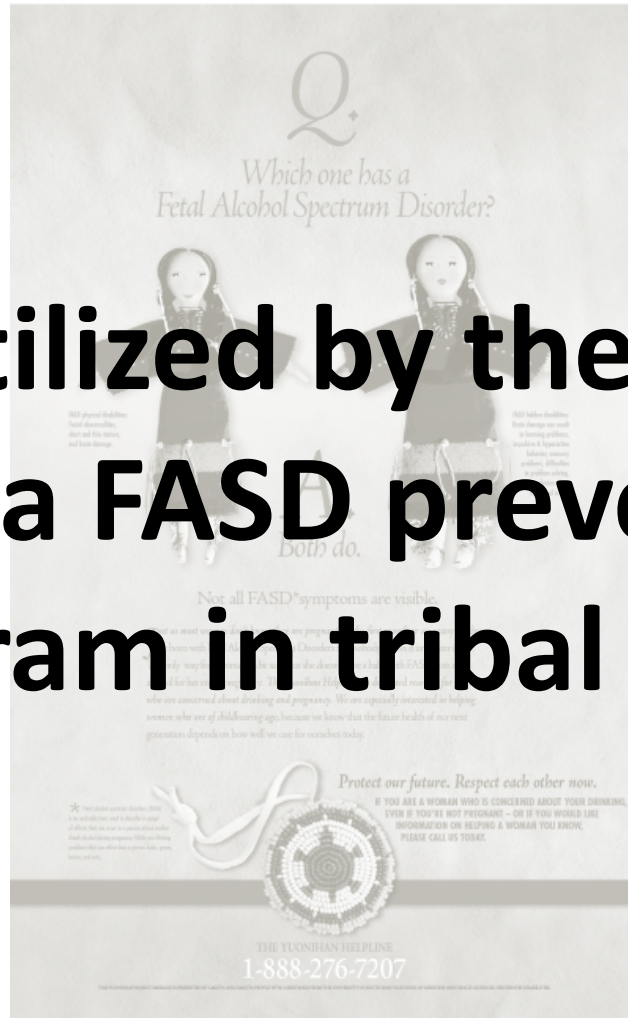
# AEP Risk Defined

- Any sexually active woman of reproductive age who is drinking alcohol and not using birth control is at risk for an alcohol-exposed pregnancy.
- A developing baby can be exposed to alcohol before a woman knows she is pregnant.

# Risk of Alcohol-Exposed Pregnancy

- Average amount of alcohol consumed was 7.0 drinks per occasion.
- Number of drinks in an average week was 13.0.
- Average “most drinks at one sitting” was 9.7 drinks
- 30% indicated using no protection while engaging in sexual activity.

# Data utilized by the tribe to fund a FASD prevention program in tribal clinics



Funding from the Centers for Disease Control and Prevention,  
U84/CCU823298 (Elliott, Burd & Hanson)

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# Background on Project CHOICES

- Major effort to decrease risk for alcohol-exposed pregnancy (AEP) among non-pregnant women.
- Four face-to-face MI sessions over several weeks, with a separate contraception counseling session.
- Overall, the Project CHOICES intervention significantly decreased the risk of an AEP.

**Sources:**

Floyd RL, et al. (2007)

Ingersoll KS, et al. (2003)

Floyd RL, Ebrahim SH, Boyle CA.. (1999)

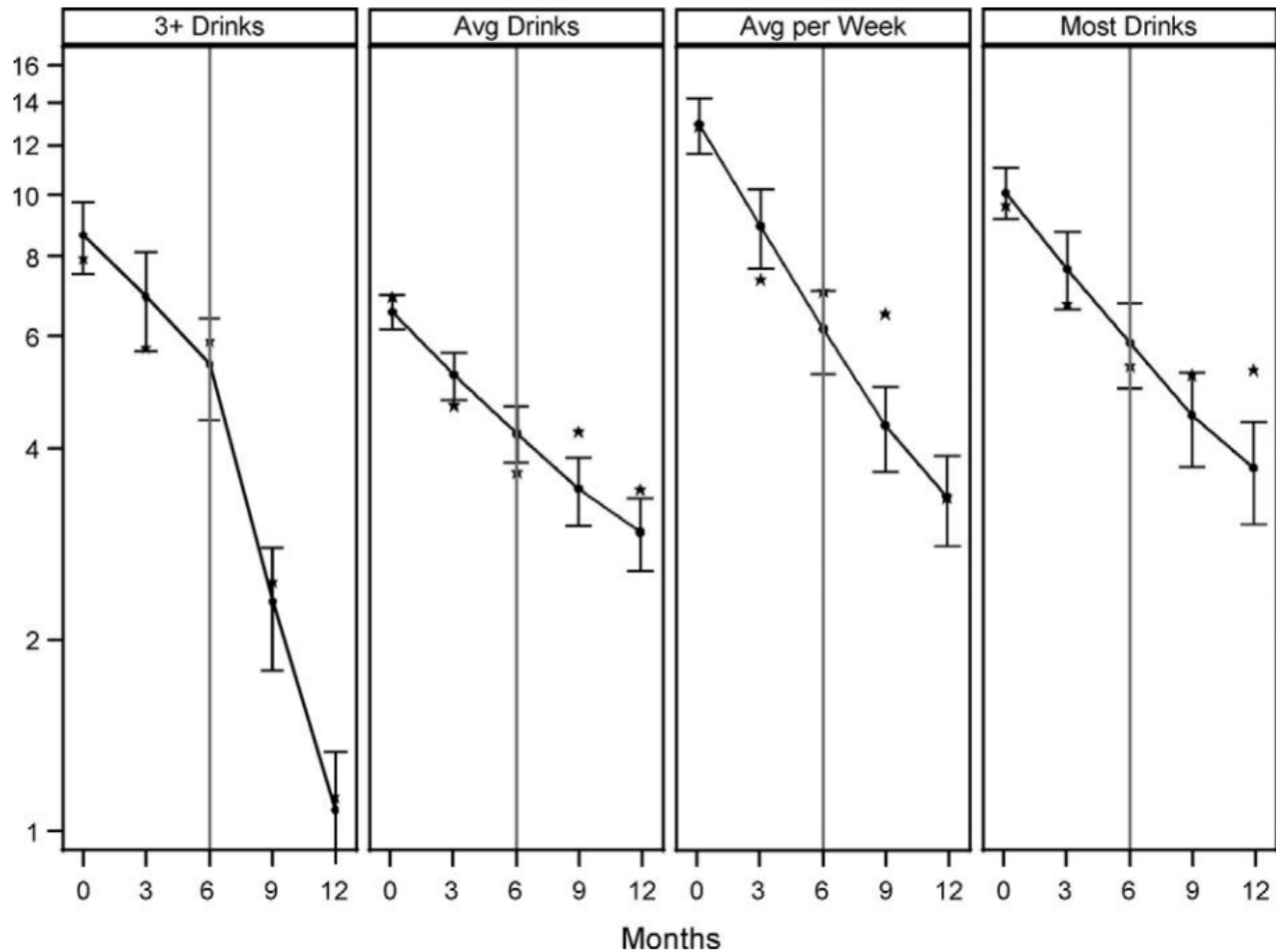
Sobell M, et al. (2003)

# *Yuonihan* Intervention

- Five questionnaires via the telephone, including baseline.
- After each of the five surveys, participants were sent intervention materials: personalized feedback on how their risk for AEP compared to other women and a workbook.
- Follow-up phone calls occurred at 3, 6, 9, and 12 months after the baseline call.

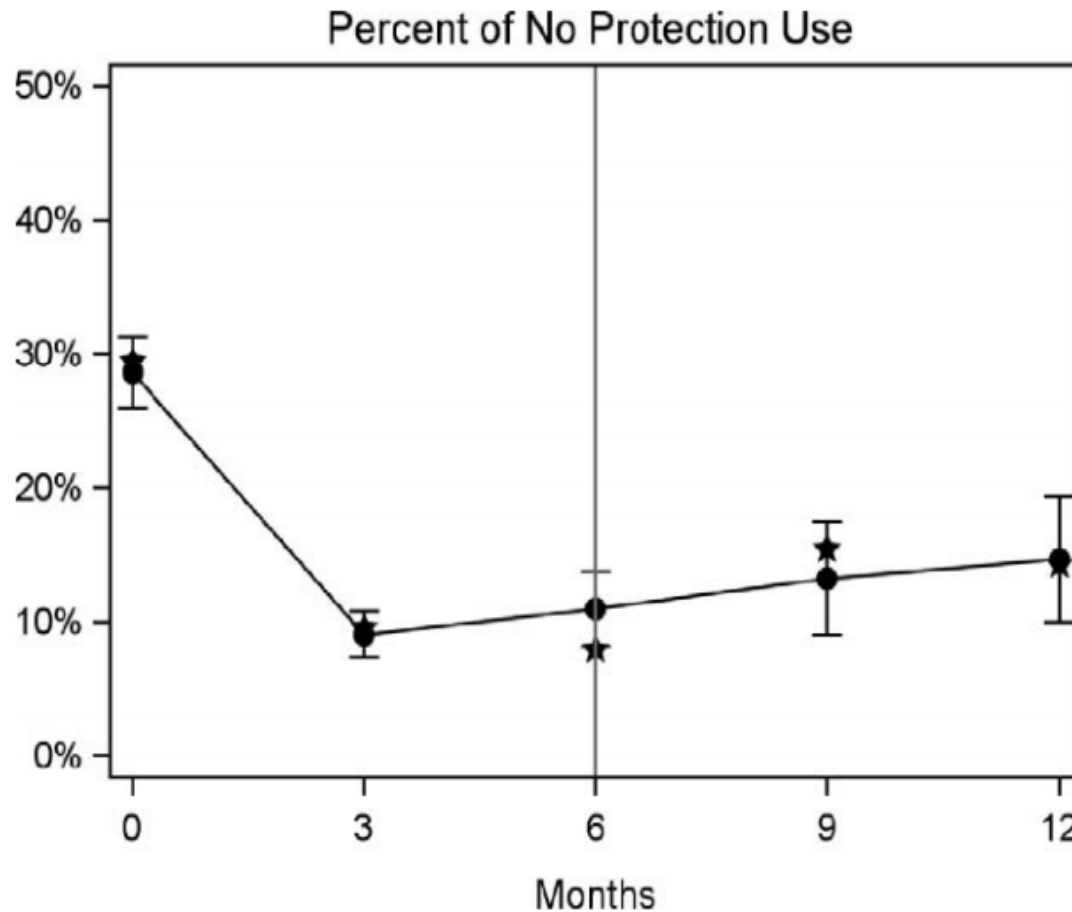


### Time Trends of Drinking Behaviors at Each Visit, With 99% Confidence Intervals



Hanson, J.D., Miller, A.L., Winberg, A., & Elliott, A.J. (2013). Prevention of alcohol exposed pregnancies with non-pregnant American Indian women. [American Journal of Health Promotion, 27\(3\), S66-S73. PMID: 23286666.](#)

## Time Trend for Percentage of Participants at Each Visit not Always Using Protection During Intercourse, With 99% Confidence Intervals



Hanson, J.D., Miller, A.L., Winberg, A., & Elliott, A.J. (2013). Prevention of alcohol exposed pregnancies with non-pregnant American Indian women. [American Journal of Health Promotion, 27\(3\), S66-S73.](#) PMID: 23286666.

# Results: Participant Retention

	Baseline n (%)	3 mth n (%)	6 mth n (%)	9 mth n (%)	12 mth n (%)
Drinking					
3+ Drinks	225 (97.4)	113 (48.9)	76 (32.9)	59 (25.5)	46 (19.9)
Avg. Drinks	227 (98.3)	112 (48.5)	73 (31.6)	58 (25.1)	45 (19.5)
Avg./Week	220 (95.2)	108 (46.8)	70 (30.3)	52 (22.5)	39 (16.9)
Most Drinks	228 (98.7)	115 (49.8)	76 (32.9)	60 (26.0)	47 (20.3)
Birth Control	162 (70.1)	78 (33.8)	52 (22.5)	34 (14.7)	30 (13.0)

Hanson, J.D., Miller, A.L., Winberg, A., & Elliott, A.J. (2013). Prevention of alcohol exposed pregnancies with non-pregnant American Indian women. [American Journal of Health Promotion, 27\(3\), S66-S73.](#) PMID: 23286666.

# Our Conclusions

- The intervention, adapted from the CHOICES research, was successful in changing drinking and birth control behavior for American Indian women.
- Test the feasibility and effectiveness of traditional CHOICES intervention (1:1) for American Indian women.

# Feasibility, Accessibility, and Implementation



Funding from Indian Health Services, HHS-2010-IHS-MHCEP-0001  
(Dillon, PI; Hanson, Evaluator)

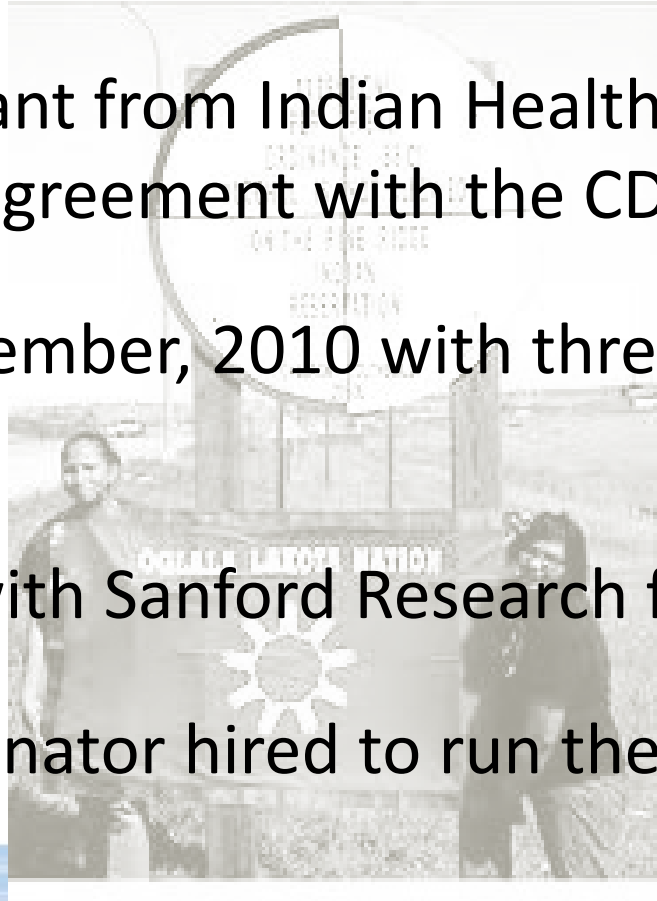
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The Oglala Sioux Tribe (Pine Ridge Indian Reservation) is 3,468 square miles located in the southwest corner of South Dakota.



# OST CHOICES Program

- Three-year grant from Indian Health Service through inter-agency agreement with the CDC
- Began in September, 2010 with three sites (one later dropped out)
- Subcontract with Sanford Research for evaluation
- Project Coordinator hired to run the project



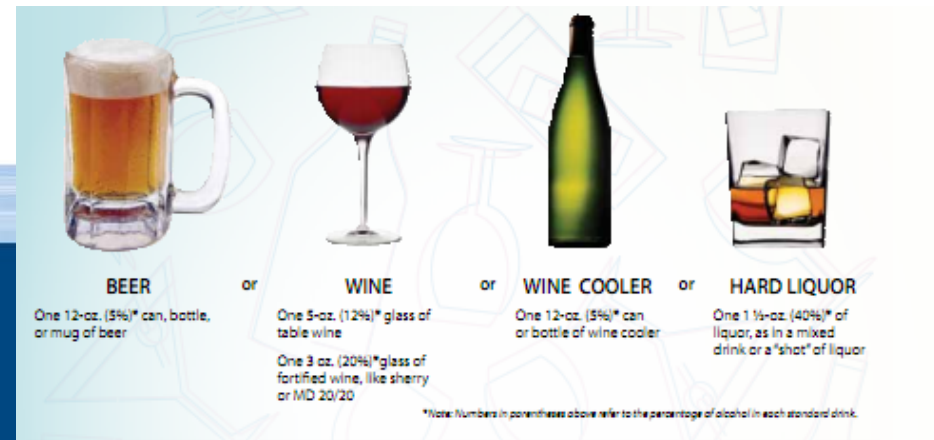
# Initial Meetings and Presentations

- Introduce the project to clinic staff and discuss questions/concerns.
- Results:
  - Concerns: benefits of this project for the patients, the clinic, and the tribe overall
  - Intervention: should be conducted by someone located within the clinic
  - Other logistical issues



# Revisions to CHOICES

- Culturally appropriate images and color
- Check readability of the materials
- Common types of alcohol consumed
- Certain types of birth control
- Risk of AEP locally



# Challenges and Solutions

- Busy/overworked staff
- Need for additional training
  - Train the trainer opportunities
- Recruitment
  - Buy-in of key clinic staff
  - Grassroot recruitment/word-of-mouth
  - Importance of incentives

# Accomplishments

- Garnered input and support from clinic staff and the tribe
- Implemented CHOICES in busy clinics
- Enrolling high-risk women, high follow-up retainment
- Presented project information back to the community

# Lessons Learned

- Importance of CHOICES being tribally-run
- Input on materials, intervention; review and final approval (CBPR)
  - Need for key contacts—someone to “sell” the program
  - Need to also gather *community* input (not just from clinics)

# Lessons Learned (cont.)

- Desire and openness for birth control
- Various types of alcohol consumed
- Ability and willingness to be flexible (2 versus 4 sessions)
- Address sustainability, such as through third-party billing and ToT program

## Reference:

Hanson, J.D. & Pourier, S. (2015). The Oglala Sioux Tribe CHOICES Program: Modifying an existing alcohol-exposed pregnancy intervention to use with an American Indian community. International Journal of Environmental Research and Public Health, 13 (1). PMID: 26703670.

# Current Status/ Preliminary Data



Funding is from award # 1R24MD008087 from the National Center on Minority Health and Health Disparities (Hanson, PI)

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# OST CHOICES Program

<b>Sioux Falls:</b>	<b>Jessica Hanson, PhD (PI)</b>		<b>Jamie Jensen, MS (Senior Research Associate)</b>
<b>Pine Ridge:</b>	<b>Jacque Jacobs-Knight, AA (Program Coordinator &amp; Interventionist)</b>		
<b>Kyle:</b>	<b>Katana Jackson, MSW (Interventionist)</b>		<b>Christina Janis, MA (Interventionist)</b>
<b>Rapid City:</b>	<b>Amy Willman, RN (Site Coordinator &amp; Interventionist)</b>		

## ❖ Sites

- ❖ Pine Ridge – 2-sessions, one-on-one or Group CHOICES
- ❖ Kyle – 4-sessions, one-on-one
- ❖ Rapid City – Group CHOICES

*\*\*All sites include a contraceptive counseling session with a health care provider.\*\**

- ❖ All sites also include a 3- and 6-month post-intervention follow-up to assess alcohol and contraception behaviors.



# 3-Month Behavior Changes

- 218 women enrolled.
- Of the 159 women reached, 120 (75.5%) were at reduced risk for an AEP.
  - Of these, 58.5% reduced their drinking; 38.4% increased their use of birth control; and 27.0% improved both behaviors.

# 6-Month Behavior Changes

- Of the 106 reached, 74 (69.8%) were at reduced risk for AEP.
  - Of these 106, 63.2% reduced their drinking; 31.1% increased their use of birth control; and 17.0% improved both behaviors.

**Contact information:**

Jessica D. Hanson, PhD

Sanford Research

2301 E. 60<sup>th</sup> Street North

Sioux Falls, SD 57104

Phone: 605-312-6209

Email: [jessica.d.hanson@sanfordhealth.org](mailto:jessica.d.hanson@sanfordhealth.org)

Website: [www.sanfordresearch.org](http://www.sanfordresearch.org)

# Access & Utilization of Local Data

Wyatt Pickner BA, BS

Research Associate  
Sanford Research



# Outline

- Define local data
- Discuss local data issues
- Identify existing sources and gaps
- Discuss community health assessments
- Provide strategies for improvement



# Local Data

- Community level information
  - Demographics
  - Health indicators & outcomes
  - Physical characteristics
    - Environment
    - Infrastructure
- Rural communities = counties



# Utilization

- Government agencies
  - Policy and legislation
- Clinics & health systems
  - Services
- Research & community organizations
  - Program development & evaluation



# Local Data Issues

- Rural communities/populations
  - Limited publically available
- AI communities
  - Typically in rural areas
  - Overlap county/state/national borders
- Know the problems
  - Don't understand why or the causes
  - Little or no data to support community concerns





# Examples of Current Local Data

- Department of Health
  - State/City
  - Tribal agencies
- National/Regional
  - Census
  - CDC
- Research Studies
- Health organizations
- Other programs/organizations



# Health Indicator Category

- Data
  - Demographic
    - Age, race, gender
  - Health
    - Vital statistics, chronic & infectious disease
  - Education
    - Level of completion
  - Economic
    - Employment and poverty



# Current Data Gaps

- Work with specific communities to identify what is missing
  - Each community is different
  - Identify needs and priorities



# The Importance of Local Data

- National/Regional data is high level
- Tells a community story
  - Problem areas
    - Set health priorities
    - Research agenda
  - Successes



# Community Health Assessments (CHA)

- “A systematic examination of health status indicators for a given population that is used to identify key needs, concerns, and assets in a community.”
  - Tailored community decision-making
  - Prioritize concerns
  - Strategies to address community needs & strengthen assets



# Methods and Models

- Mobilizing for Action through Planning & Partnerships (MAPP)
  - Comprehensive approach, requires 4 assessments, could take up to 2 years
- Good Health & Wellness Approach/Method
  - Shorter time frame, more flexibility, timeframe could be about 1 year
- Community Health Assessment and Group Evaluation (CHANGE)
  - Developed by the CDC, meant to be done annually, examines policy systems



# CHA Planning & Development

- Organizing a team
- Identify goals/objectives
- Survey/tool development
  - Types of questions
  - Topics
- Identify sampling method



# Tribal Nations Research Group

- Community Health Assessment
  - Good Health & Wellness
  - Hopes to use primary data to fill in gaps of secondary data
    - Vital records, IHS, Tribal epidemiology center, Tribal programs
- TNRG Vision
  - Development of a center for tribal data





# Strategies for Improvement

- Community Health Assessment
  - With process improvement
- Comparable metrics
  - Across “borders”
- Relationship building



# Regional and national data for health indicator measurement

Susan Puumala, PhD

Associate Scientist  
Sanford Research

Associate Professor  
Departments of Pediatrics and Internal Medicine  
University of South Dakota Sanford School of Medicine



# Outline

- Regional and national health indicators and data
- Issues with the data
- Use of health indicators
- Modeling approaches to potentially improve data



# Health Indicators and Data

- Possible sources of data
  - Census data
  - State mortality data
  - State cancer registry
  - BRFSS data and other CDC surveys
  - EPA or other environmental agency
  - Bureau of Labor Statistics
  - IHS and other health care data
  - Research studies
  - Community data
    - Community Assessments
    - Housing
    - Education



# Data issues

- Availability of data
- Methods of data collection
  - Reason the data was collected
  - Possible biases associated with the data
- Representiveness of data
- Consistency of data over time
- Consistency of data over space
- Aggregation of data
- Community interest in data that crosses geographic boundaries



# Health Indicators and Data

- Health Indicators



<http://www.countyhealthrankings.org/>



# South Dakota Profile

	Non-Hispanic White	Non-Hispanic Black	Hispanic	American Indian/Alaskan Native	Asian/Pacific Islander	State Total	Healthy People 2020 National Target	State Rank
Population (2012) (all ages)	84.8	2.0	3.1	9.5	1.2	833,354		
Major causes of death (rate per 100,000)¶								
All cause	678.7	444.2	364.6	1,317.2	588.1	714.9	+	17
Heart disease	151.7	*	*	205.9	*	155.2	+	17
Coronary heart disease	118.1	*	*	173.0	*	121.3	100.8	32
Total cancer	168.4	*	*	242.8	*	171.0	160.6	22
Colorectal cancer	17.0	*	*	*	*	17.0	14.5	35
Lung cancer	44.5	*	*	63.5	*	45.3	45.5	20
Stroke	39.7	*	*	52.1	*	39.9	33.8	29
Chronic obstructive pulmonary diseases (age 45 & over)	123.8	*	*	193.1	*	125.4	98.5	30
Diabetes-related	72.3	*	*	266.4	*	80.3	65.8	38
Influenza and pneumonia	14.9	*	*	40.0	*	15.8	+	28
Unintentional injuries	37.3	*	*	126.8	*	44.5	36	40
Suicide	15.5	*	*	31.0	*	17.5	10.2	45
Health risk factors (percent) §								
Diagnosed high blood pressure (2011)	28.6	*	24.9	39.9	*	29.8	26.9	23
Obesity (2012) (age 20 & over)	27.7	*	27.5	36.9	*	28.3	30.6	27
No leisure-time physical activity (2012)	21.2	*	16.9	30.0	*	21.9	32.6	23
Smoking currently (2012)	19.4	*	26.1	53.1	*	22.6	12	37
Eats 5+ fruits and vegetables a day (2009)	15.2	*	16.8	16.5	*	15.3	+	53
Preventive care (percent) §								
Cholesterol screening in past 5 yrs. (2011)	71.3	*	68.9	63.2	*	70.6	82.1	39
Routine check-up in past 2 yrs. (2012)	78.3	*	79.5	76.9	*	78.3	+	34
Dental visit within the past year (2012)	73.2	*	60.0	59.5	*	71.3	+	9
Health insurance coverage (percent)								
Health insurance coverage (2012) (ages 18–64)	86.4	*	78.5	89.6	*	86.2	100	9

# CDC Health Disparities and Inequalities Report (CHDIR)

- Death and illness
- Use of health care
- Behavioral risk factors for disease
- Environmental hazards
- Social determinants of health





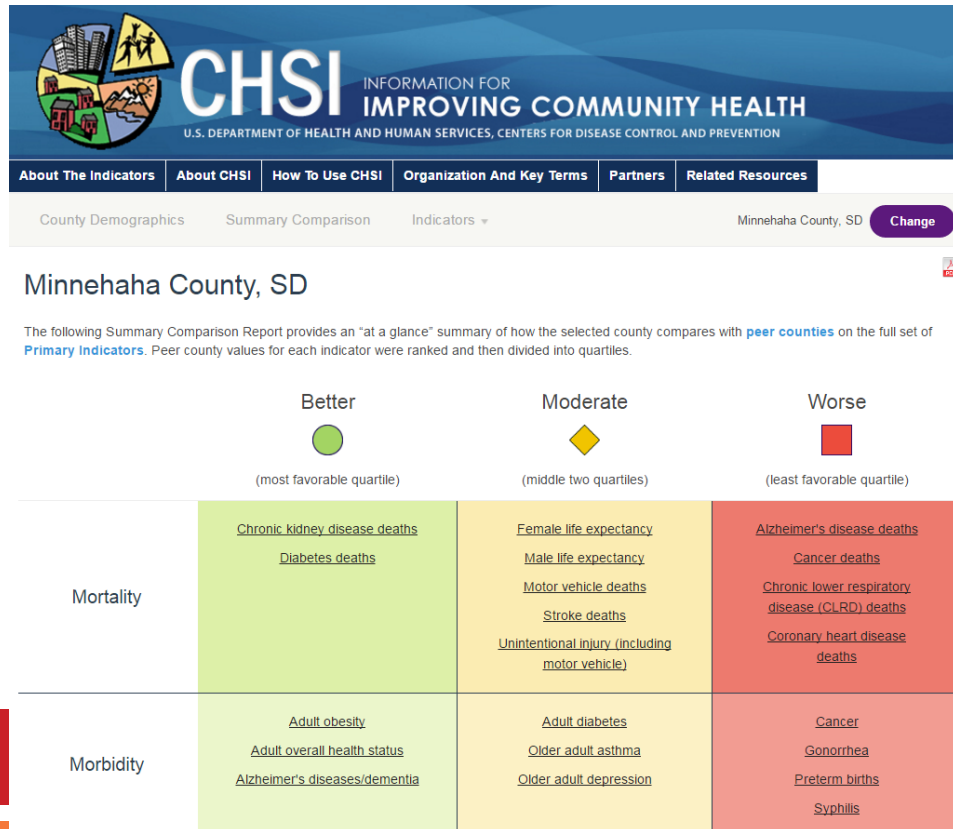
# Health Indicators and Data Summary

- Some data exists
  - Usually county level data
  - Could potentially seek more specific data
- Possible data issues
  - Inconsistency in data available by state and by county
  - Lag in current year data release or not available in all years
  - Small numbers/data quality
  - Limited geographic detail
- Many other groups have looked at this data



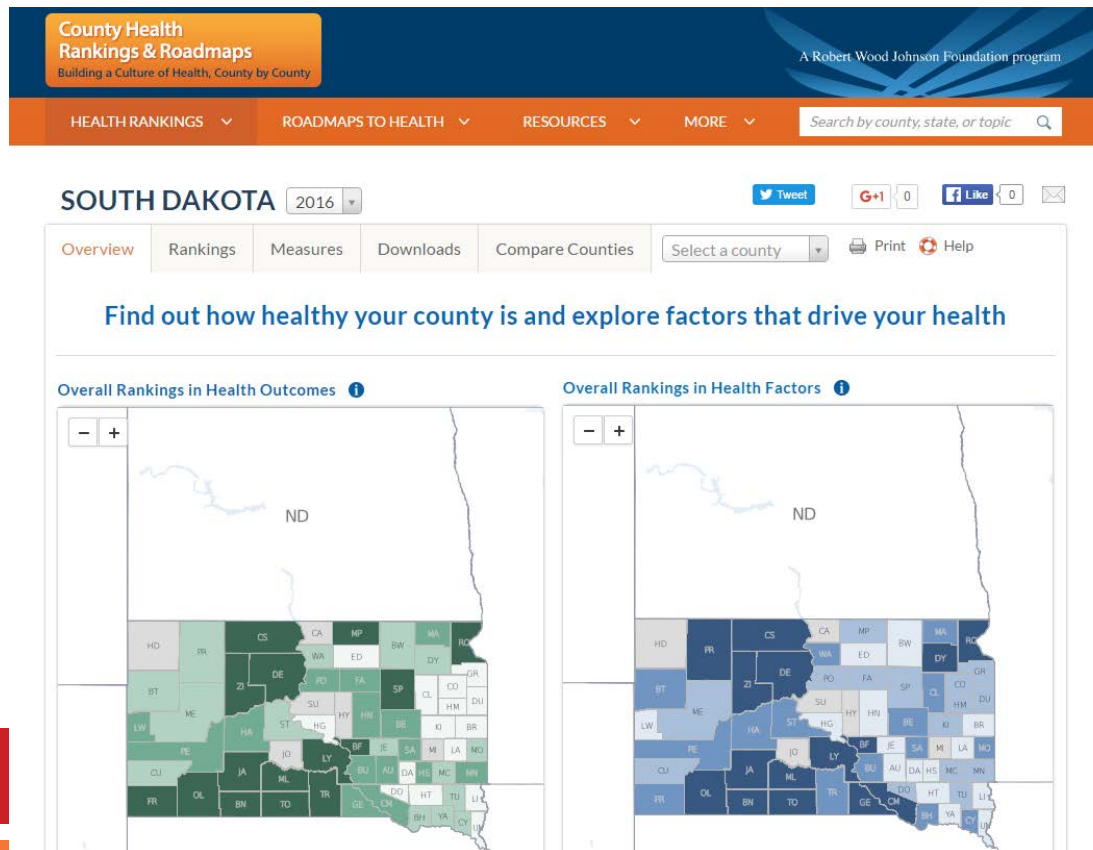
# Can we use this data in a meaningful way?

- Individual health indicators to provide insight for local communities



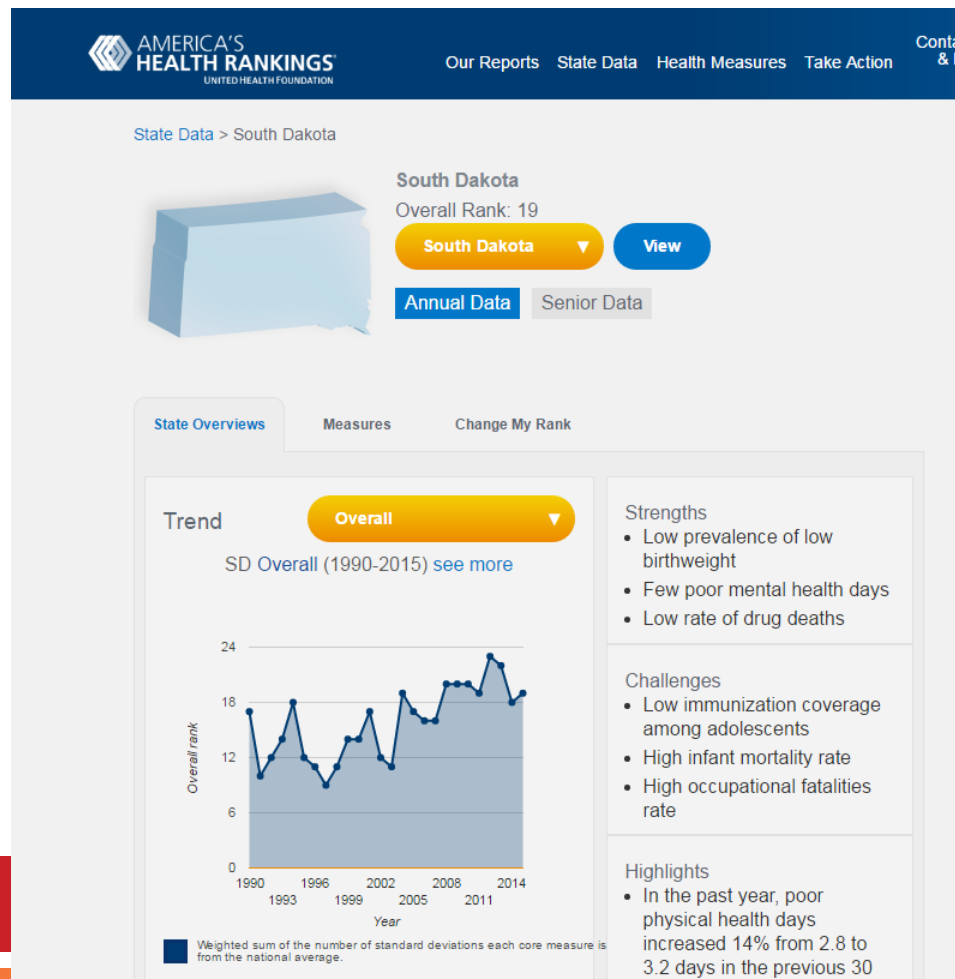
# Can we use this data in a meaningful way?

- Composite that tells us something about overall health



# Can we use this data in a meaningful way?

- Tracking overall changes over time

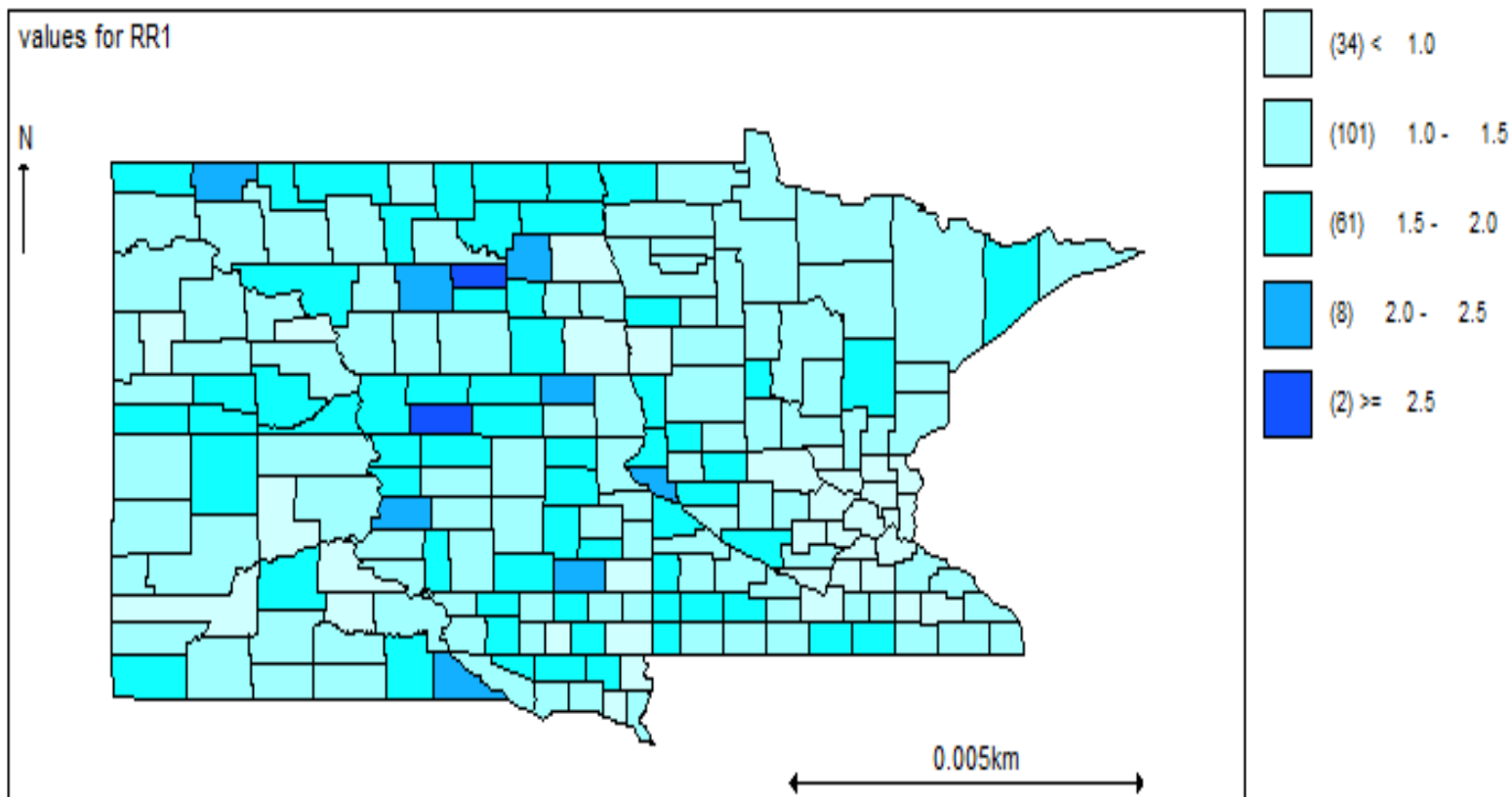


# Example: Mortality

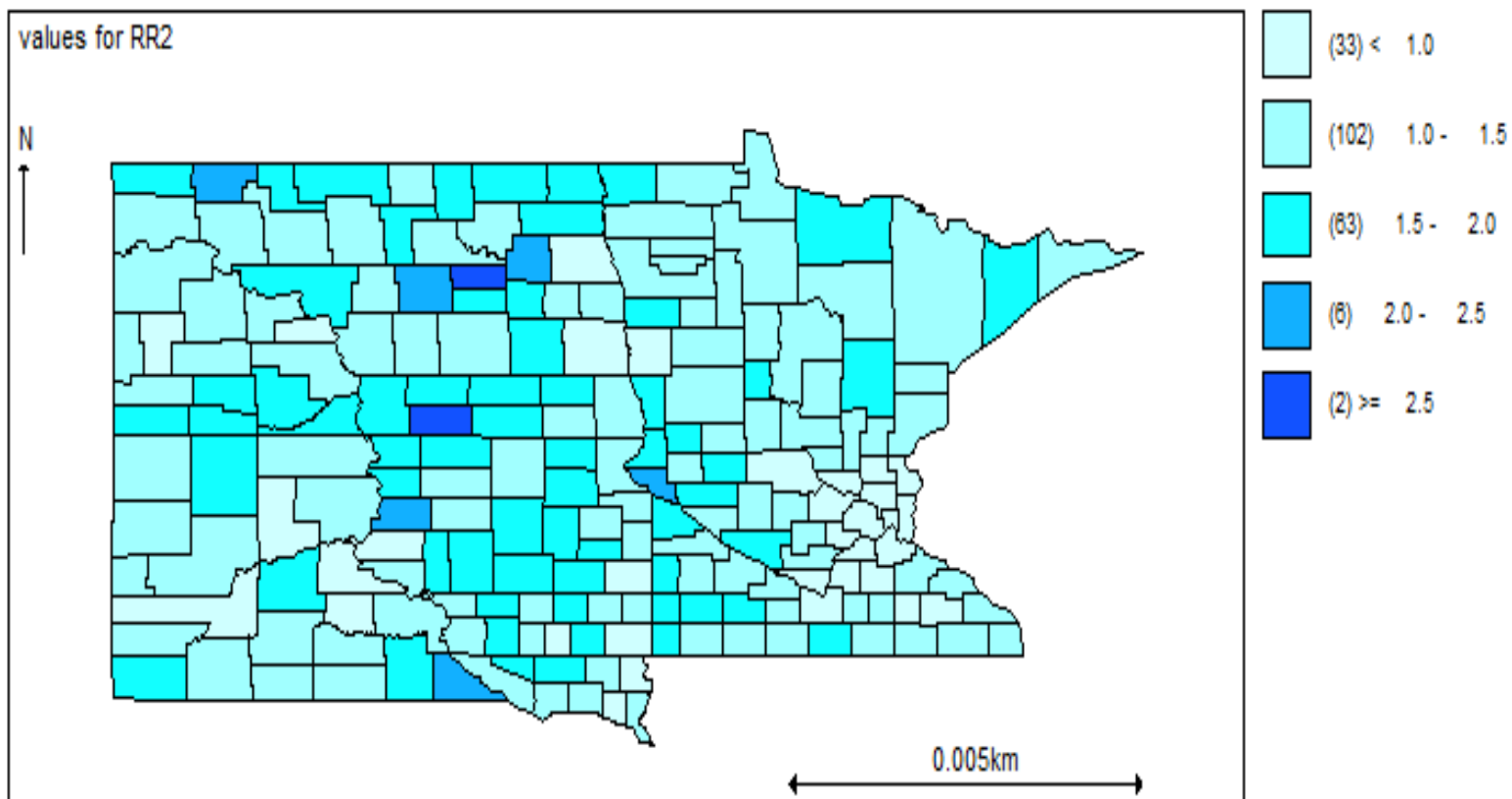
- Data from 2008-2013
- Counties in SD, ND, and MN
- Raw number of deaths (not adjusted for age)
- Includes expected value
  - What if rate were the same in all counties in a year?
  - Standardized by the population in each county
- Spatial model with linear time trend



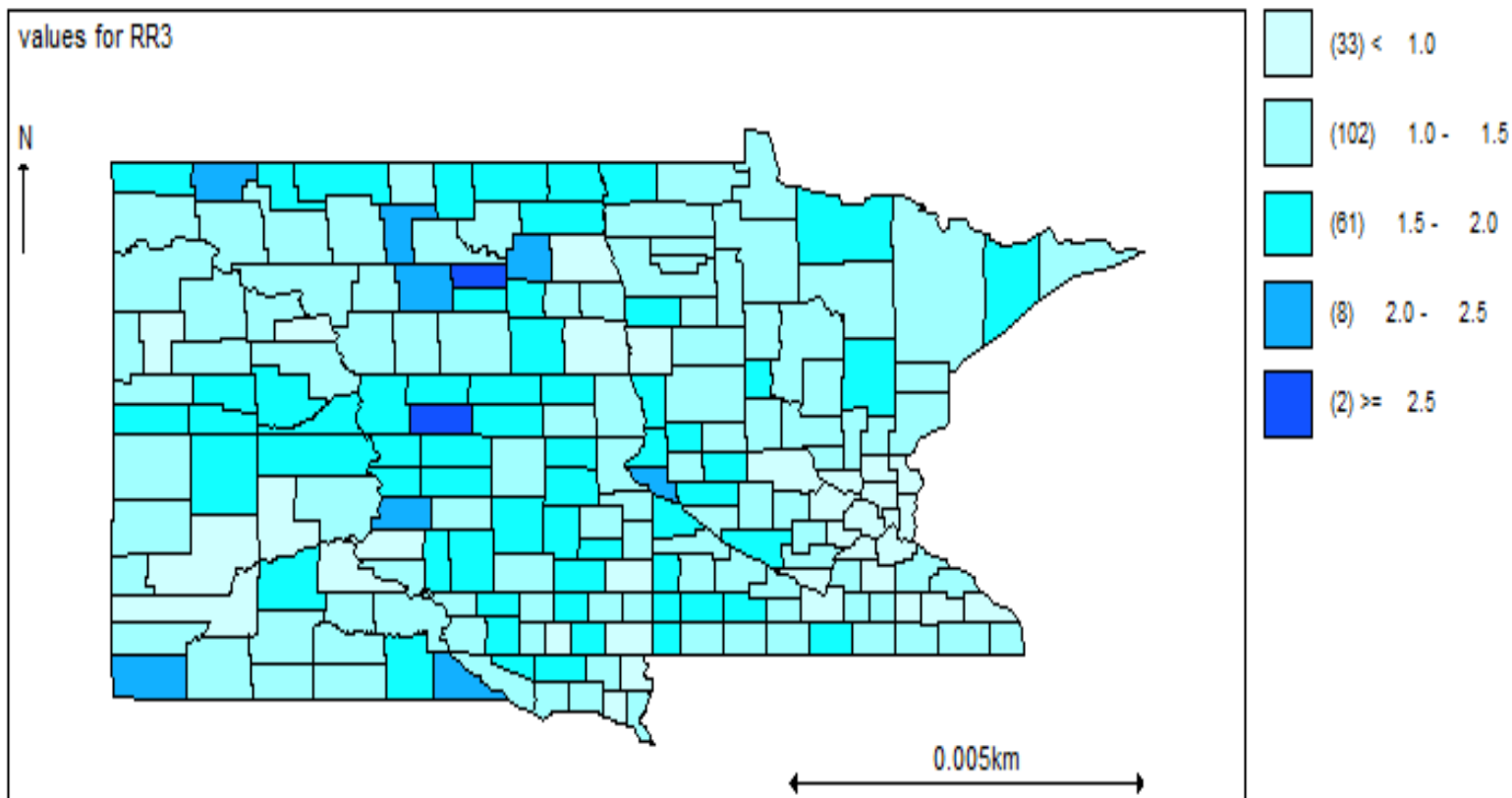
# RR at 2008



# RR at 2009

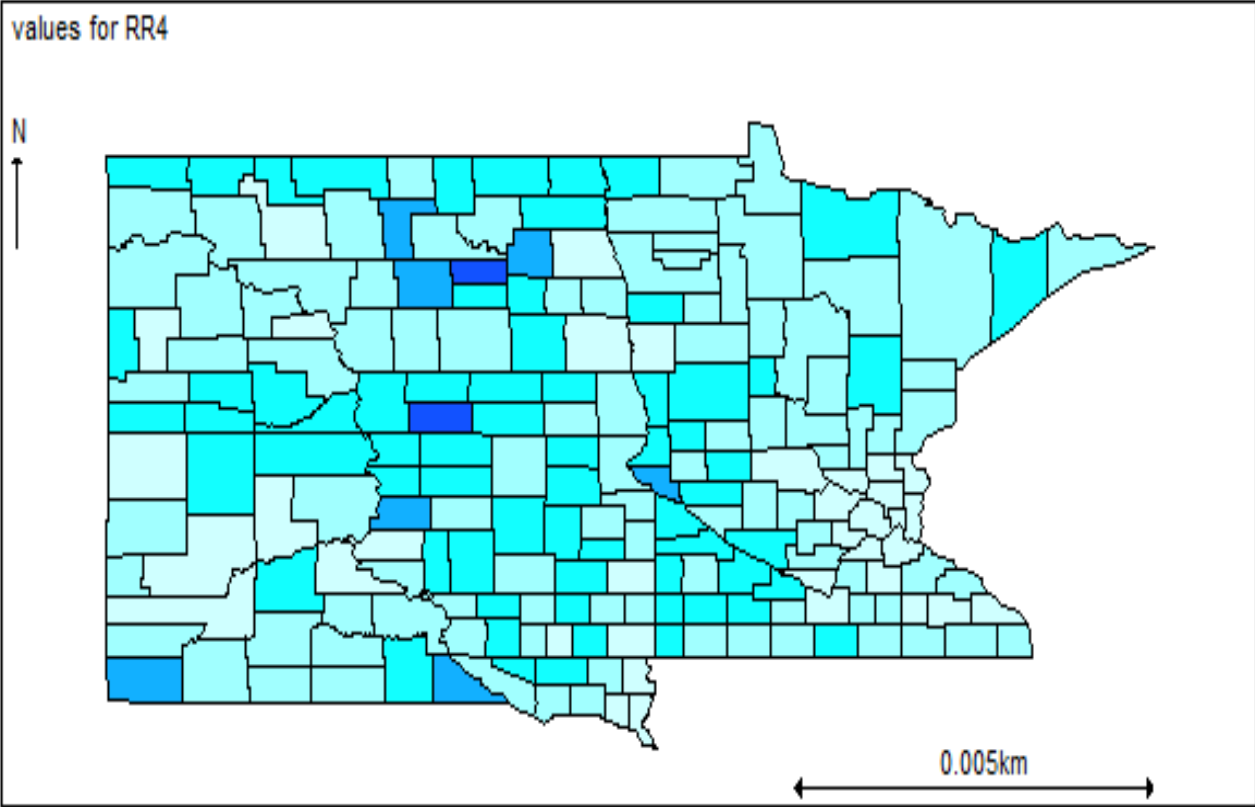


# RR at 2010

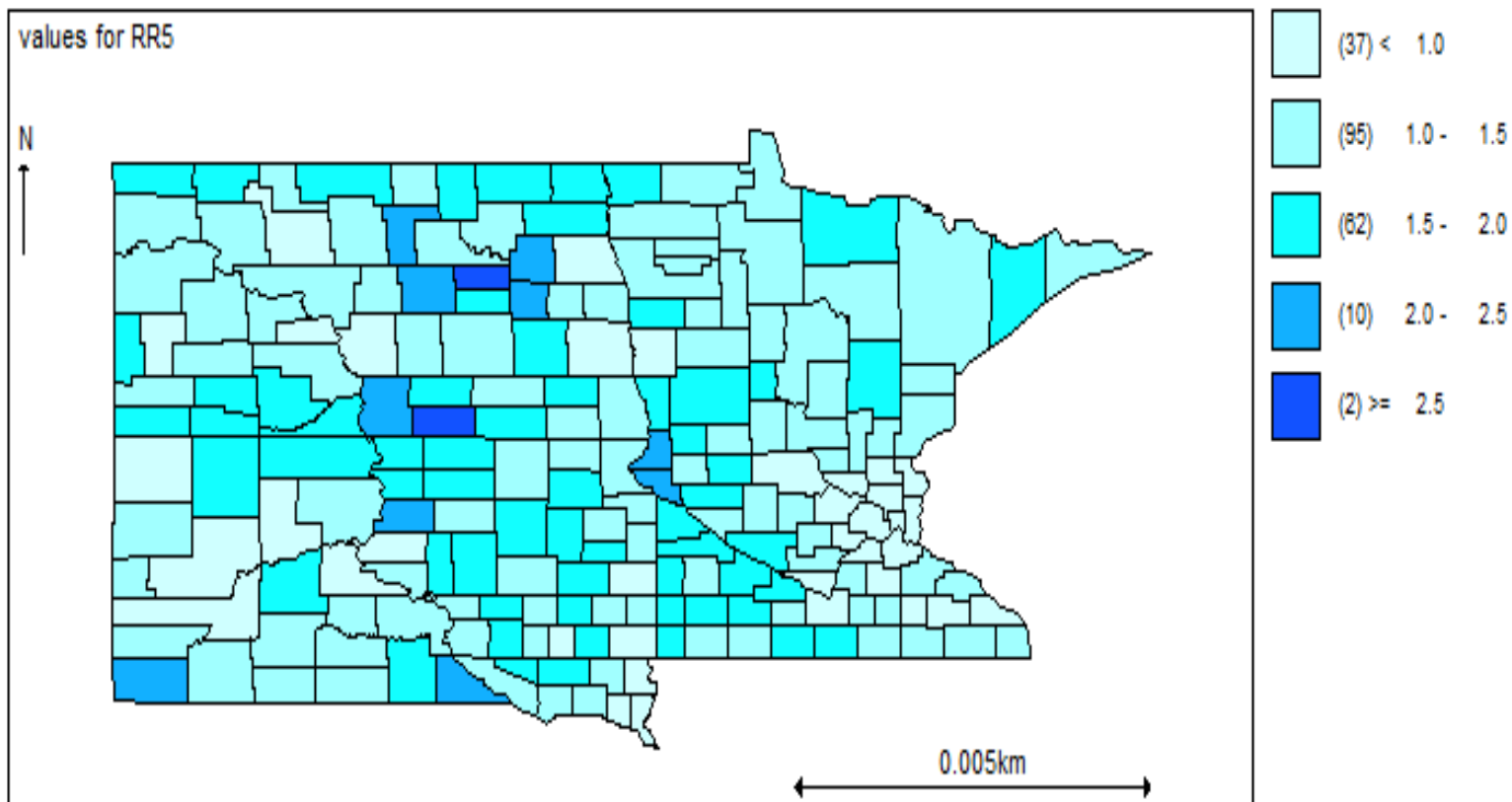




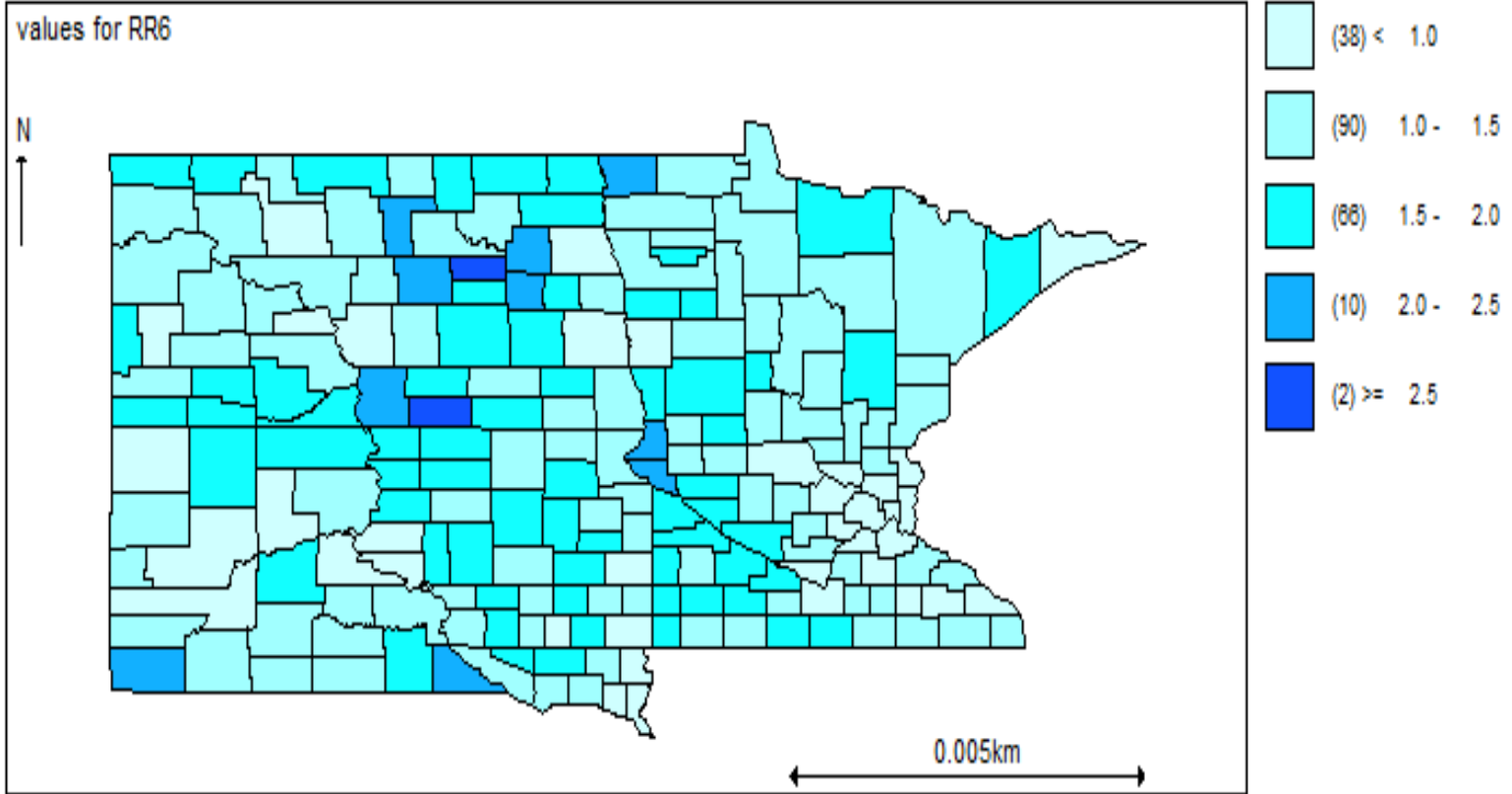
# RR at 2011



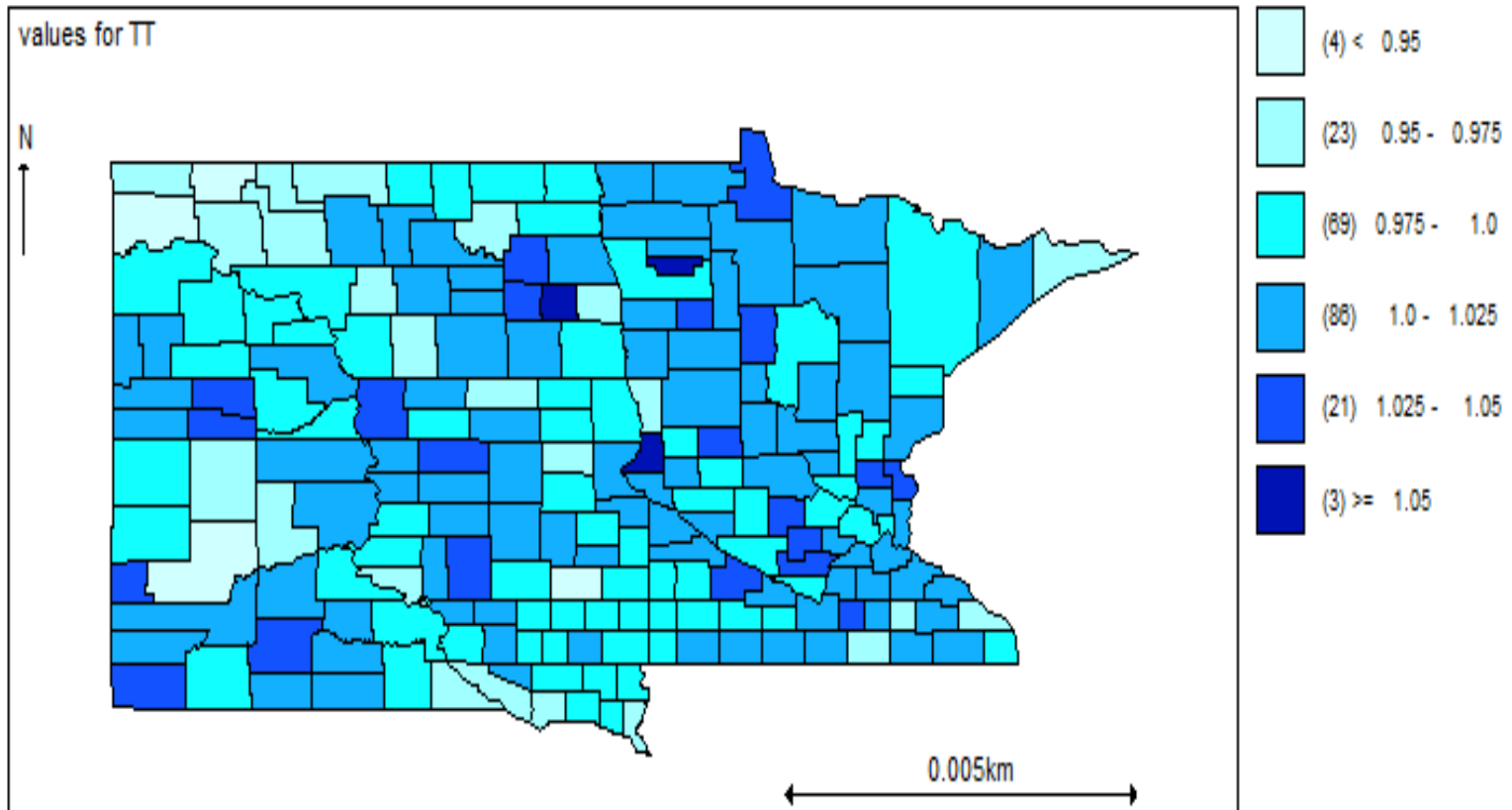
# RR at 2012



# RR at 2013



# Overall time trend (TT)



# Measuring Overall Health

- How can we take a set of variables and turn them into a meaningful index?
  - Overall health
  - Overall disparity
  - Different domains within health/disparity
- Use Structural Equation Modeling
  - Nothing but regression
  - Combines factor analysis and regression



# Latent variable

- Unobserved, unmeasured, factors, constructs
- Attitude, satisfaction, overall health
- Social sciences and other disciplines
- Exogenous (independent) or Endogenous (dependent)
- Use statistical methods to measure latent variables through observed variables



# Health Indicators as Latent Variables

- Health Indicators
- Could be standardized to measure disparity
- Overall goal is to explore changes over time



<http://www.countyhealthrankings.org/>



# Spatial Adjustment and Smoothing

- Need a way to smooth the data over areas
  - Accounts for small numbers in a particular county
  - May help map counties to community areas
- Can also model spatially adjusted data to predict outcome and look for spatial trends
- Bayesian models provide a framework for smoothing and incorporation of prior data





# Assessing changes

- How do we measure changes over time
- Spatial model
  - Counties adjacent to one another are more alike than those not adjacent
- Time model
  - Trend over time (e.g. linear, quadratic)
  - Year to year changes



# Modeling extensions

- Use multiple data sources with different geographic/time basis
- Incorporate local data to help calibrate regional/national data
- Weighting or other methods to better represent communities



# Summary

- Some data exists on health indicators over time and space
  - Assess individual indicators
  - Measure overall health
  - Describe trends over time
- Potential for use to measure health over time to assess overall improvement/decline
- Additional modeling strategies may be helpful to overcome data shortcomings

