A Collaborative Community Health Assessment for an American Indian Tribe in Wisconsin
The Importance of Local Level Data in American Indian/Alaska Native Populations

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Outline

• **Current Available Data**
  - National Level Data
    - Available Sources
    - Problems
  - State/County Level Data
    - Available Sources
    - Problems

• **The Importance of Local Level Data**
  - Applicability to program planning and resource allocation
  - Community Based Participatory Research

• **Collaborative Community Health Assessment with a Tribe in Wisconsin**
  - GLITC/GLITEC
  - Survey Development
  - Methods: Data Collection
  - Methods: Data Analysis
  - Findings
  - Limitations
  - Looking Forward
National Level Data

- Data for American Indian/Alaskan Native (AIAN) populations often limited to national-level aggregate data from governmental sources:
  - National Center for Health Statistics (NCHS)*
    *NO geographic identifiers beginning in 2005
    - National Vital Statistics System
    - Surveys
      - NHIS, NHDS, NSCH, NSFG
  - Centers for Disease Control and Prevention
    - BRFSS, YRBSS, PRAMS
  - Indian Health Services (HIS)
  - Census
National Level Data

Problems:
- Under-representation of AIAN population
- Misclassification of AIAN race
- Masking of geographic variation
Under-Representation of AIAN Population

http://www.cdc.gov/prams/States.htm
Under-Representation of AIAN Population

http://www.census.gov/geo/www/maps/ai2010_wall_map/ai2010_wall_map.html
Misclassification of AIAN Race

- 2012 study by Hoopes MJ, et al.\textsuperscript{1}
  - Cancer is leading cause of morbidity and mortality for AIANs in Pacific Northwest
  - Misclassification of AIAN race in registries causes cancer burden to be underestimated
2010 study by Johnson PJ, et al.²

- Compared regional and national rates of disparities in prenatal care utilization among AIANs
- Regional rates were significantly different from national rates, in both late prenatal care and inadequate prenatal care

Conclusion:
“Results from our current study suggest that substantive conclusions about AIAN health care disparities should be geographically specific, and conclusions drawn at the national level may be inaccurate – even misleading – for policymaking and intervention at local levels.”²
State/County Level Data

• Sources:
  ○ County Health Rankings
  ○ Indian Health Services (IHS)
    • Contract Health Service Delivery Area (CHSDA)
  ○ National Center for Health Statistics
  ○ Census
State/County Level Data

• Problems:
  ○ Underrepresentation of AIAN population
  ○ Misclassification of AIAN race
  ○ Masking of geographic variation
  ○ Tribes are sovereign Nations that do not conform to state or county boundaries
  ○ CHSDAs are not tribe-specific
Tribal Boundaries

http://www.glitc.org/web-content/images/map-road.jpg
CHSDAs

- Include counties that overlap with, or are adjacent to Indian reservations
- Many CHSDA boundaries overlap between multiple Tribes
- Not all Tribes have an IHS or Tribal Clinic
Importance of Local Level Data

- Important regional differences may exist even in small areas\(^1\)
- Current methods are limited in providing data specific to the membership of individual Tribes\(^1\)
- It is necessary to monitor health status and health care access for AIANs at relevant geographic levels\(^2\)
- Access to this data will better inform decision makers and care providers committed to improving the health status of AIANs populations\(^2\)
Importance of Local Level Data

“We may need to think differently about sampling AIAN populations, which may not fit neatly within standard research approaches to national health surveys.”³
Community-Based Participatory Research

- AIANs face significant health disparities
- Research has shown that health promotion practice research conducted by or in partnership with community-based organizations (CBOs) can address health disparities
  - CBOs possess both an interest in and access to local knowledge that can inform health priorities
Community-Based Participatory Research

- WHO Health Evidence Network report, 2006:

“...empowerment strategies, participation, and other bottom-up approaches have become prominent paradigms within public health... for reducing disparities.”

“While participatory processes make up the base of empowerment, participation alone is insufficient if strategies do not also build capacity of community organizations and individuals in decision-making and advocacy.”
Mission Statement:
“The Great Lakes Inter-Tribal Council will support member tribes in expanding sovereignty and self-determination.”

Epidemiology Center:
- Serves 34 Tribes, three Service Units and four Urban Indian Health Programs
- GLITEC is in its sixteenth year of operation, originating in 1996
- GLITEC staff strives to:
  “Support Tribal communities in their efforts to improve health by building capacity to collect and use data while advocating on the local, state and national levels to improve data quality.”
Survey Development

- Individual and household survey tools utilized.
- Developed by a team of Tribal Members and GLITEC staff.
- Overseen by the Tribal Health Director
- Included multiple open-ended short answer questions
- Requested feedback about the survey and other comments at end of individual survey
Methods: Data Collection

- Data was collected from surveys conducted during the year 2011-2012
- Survey was self-administered, using pen and paper
- Filled out at community meetings where a meal was provided
- Different collection locations on different days.
- Convenience sample
- Tribal members who answered the survey and lived within an approved list of zip codes were included
- 625 Individual surveys and 202 household surveys were collected
Methods: Data Analysis

• Data was hand-entered into excel
  ○ One spreadsheet each for individual survey data and household data

• All data points on every 10th survey entered were quality checked for accuracy
  ○ Error rate of .0013%

• Analysis occurred at GLITEC headquarters during the summer of 2012 using Statistic Analysis Systems (SAS) software

• A report was generated for the Tribe in August, 2012
Findings

- Key findings included information regarding:
  - Geographic distribution
  - Demographic distribution
  - Health status data
  - Health Behavior data
  - Social history and risk behavior data
- Open ended questions were included in each survey
- Feedback on survey administration and applicability was solicited
Limitations

- Possible restricted sample size due to inability to travel or other time commitments
- Recall bias due to self-reported data
- Inability to compare data to national standards due to non-standard wording of questions
Looking Forward

- Utilize Tribe-specific local data to inform:
  - Policy decisions
  - Fund allocation
  - Grant writing
  - Program development
Sources


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“Tell me and I’ll forget. Show me, and I may not remember. Involve me, and I’ll understand.”
- Native Proverb