

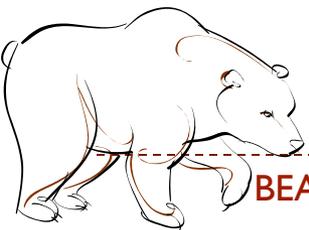
Epidemiology 101 in Indian Country

Nicole M Butt (Oneida), Owner and Evaluator
BEAR Consulting, LLC

Jacob Melson, Behavioral Health Epidemiologist
Great Lakes Inter-Tribal Epidemiology Center

*After participating in **Epidemiology 101 in Indian Country**, Attendees will be able to:*

- ▶ *Define epidemiology
- ▶ *Identify why data are important
- ▶ *Identify how epidemiology "fits into" SPF SIG



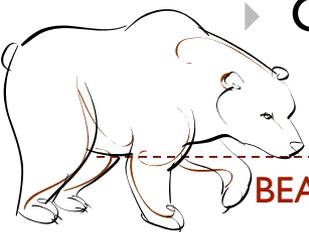
BEAR Consulting, LLC.

Butt Education and Research Consulting, LLC

- ▶ Enrolled Oneida Nation of Wisconsin
- ▶ First Gulf War Veteran- Medical Laboratory Support Stationed in Germany
- ▶ Evaluation for Tribal and non-Tribal Entities
 - ▶ Tribal School Evaluation
 - ▶ Daycare Facilities in Preparation for Accreditation
 - ▶ Disproportionate Minority Contact Study for the State
 - ▶ Economics Teacher Incentive Program
 - ▶ SPF-SIG
 - ▶ GLITC
 - ▶ GTB



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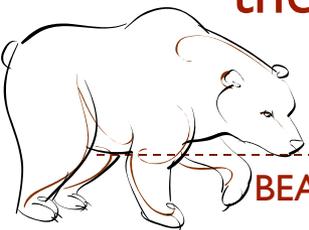
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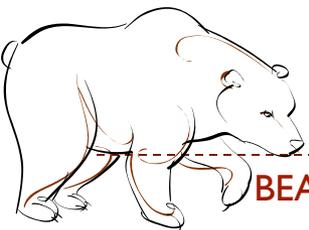
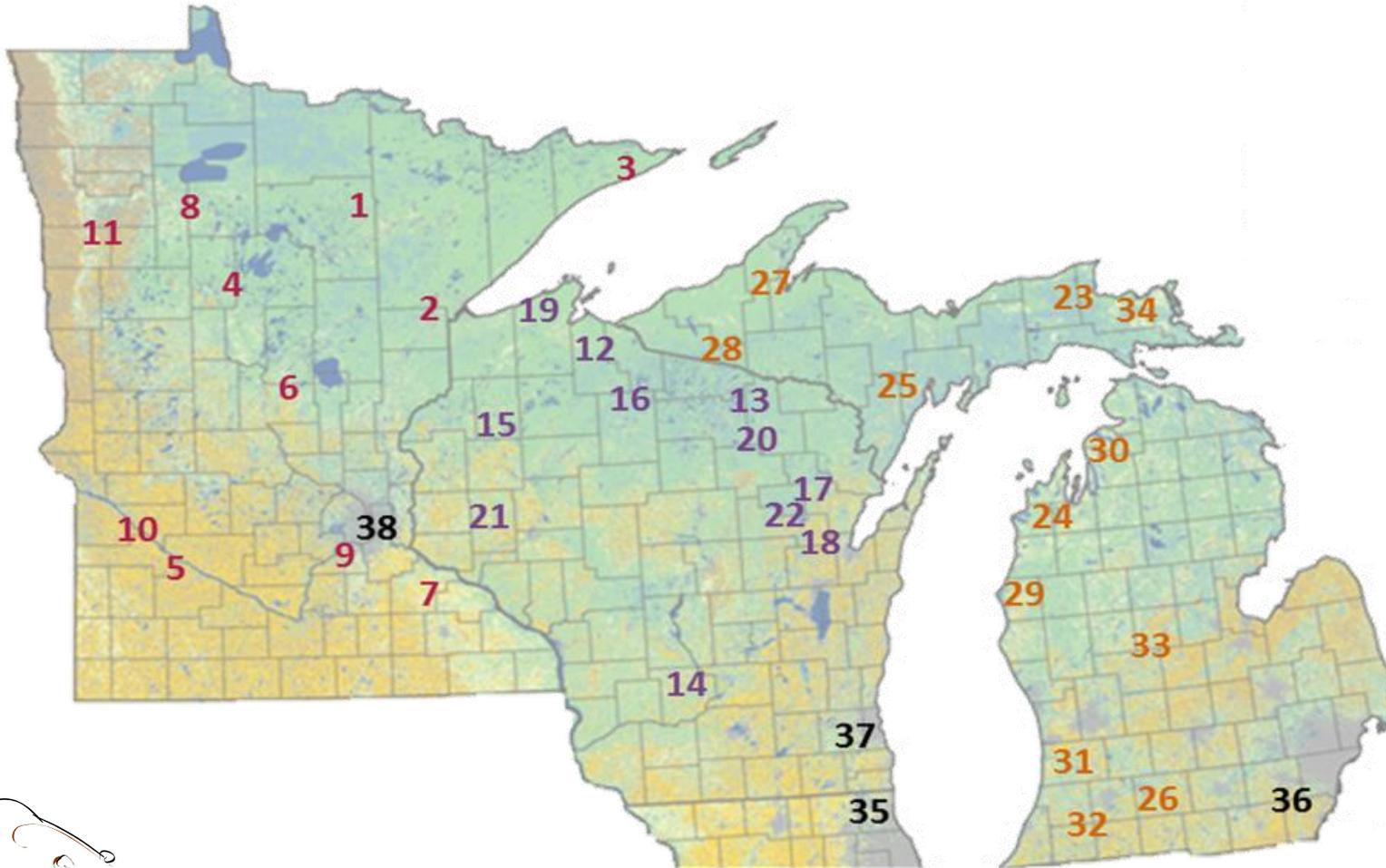
GLITEC

Great Lakes Inter-Tribal Epidemiology Center (GLITEC)

- ▶ Funded partially by Indian Health Service to serve American Indian/Alaska Native Tribal and urban communities by:
 - ▶ Managing public health information systems;
 - ▶ Investigating diseases of concern by monitoring population health status, their determinants, and threats;
 - ▶ Managing disease prevention and control programs;
 - ▶ Responding to public health emergencies, and coordinating these activities with other public health authorities.



GLITEC Member Tribes

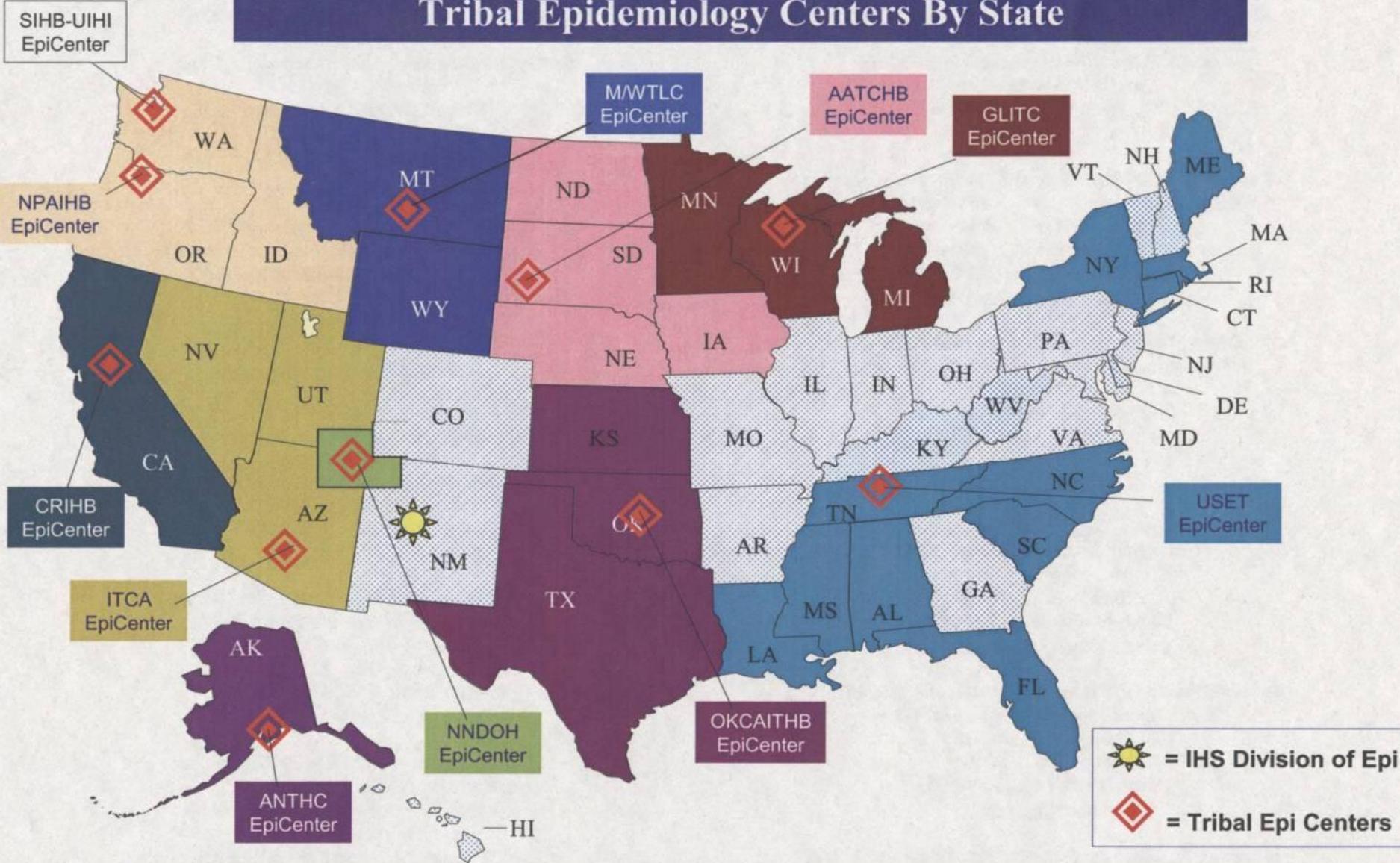


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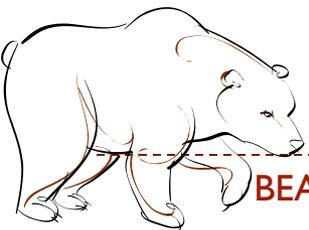
Tribal Epidemiology Centers By State



ANTHC	GLITC	MWTLC	AATCHB	OKCAITHB	USET
CRIHB	ITCA	NNDOH	NPAIHB	SIHB-UIHI <small>(See Map #2)</small>	Not covered by a TEC

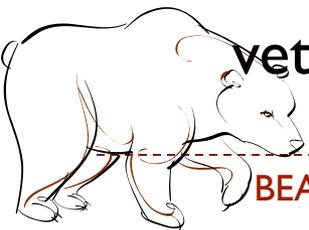
Defining Epidemiology -

- ▶ Epidemiology is the study of the distribution and determinants of health (who gets sick – or stays well – and why) and the application of this study to the control of health problems.

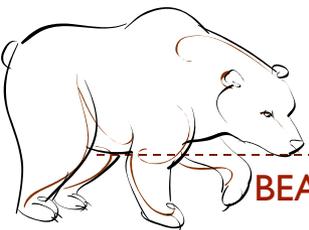


Epidemiology is Used to Answer Questions like:

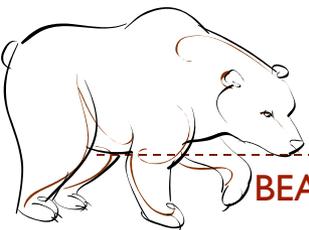
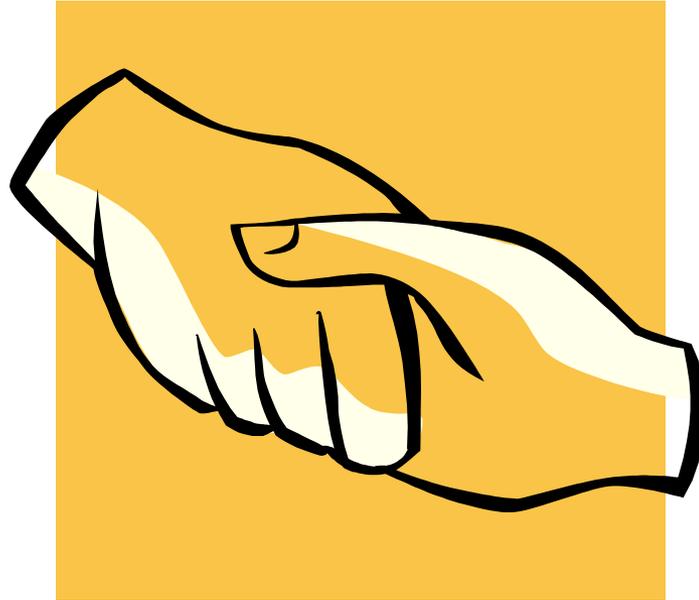
- ▶ What drugs do American Indian youth report using most frequently?
- ▶ What is the prevalence of commercial tobacco use among American Indian males?
- ▶ Is the suicide rate among American Indian youth increasing or decreasing?
- ▶ After participating in the intervention, were there statistically significant decreases in American Indian veterans overall PTSD scores?



How Epidemiology "fits into" SPF SIG/TIG



Assessment & Evaluation



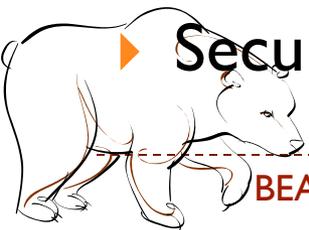
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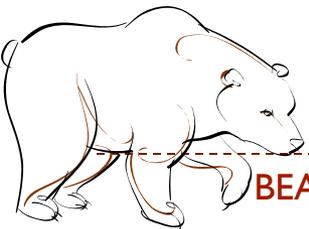
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Why are Data Important?

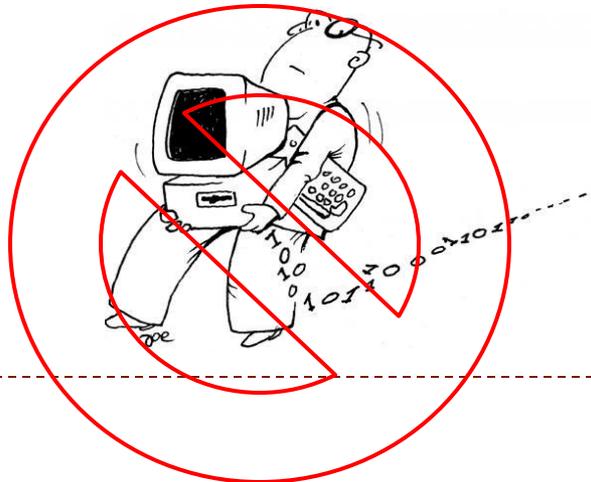
- ▶ Create buy-in
- ▶ Data-driven decisions
- ▶ Determine what is or is not working
- ▶ Prioritize needs
- ▶ Raise awareness
- ▶ Secure additional funding



Data Helps People Understand What the Issues Are... So They Support Your Work



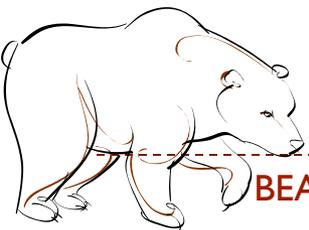
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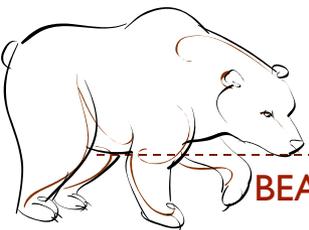
Tips for Designing Your SPF SIG/TIG Assessment/Evaluation

- ▶ Engage your stakeholders!
 - ▶ Identify who they are - think beyond your funder!
 - ▶ What are they interested in knowing?
 - ▶ What is their epidemiological capacity?
- ▶ Address issues of data ownership, control, access and possession



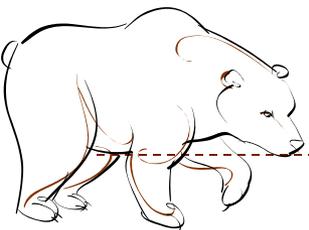
Tips for Designing Your SPF SIG/TIG Assessment/Evaluation

- ▶ Continue to engage your stakeholders
 - ▶ Evaluation - Process? Outcome? Both?
 - ▶ Is it to guide future decisions?
 - ▶ Are you trying to provide evidence to persuade?
 - ▶ Are you doing it just because the funder requires it?



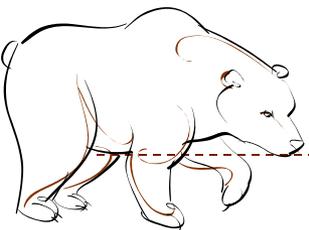
Baseline Data Collection

- ▶ Data measuring the set of conditions existing at the outset of a program/project
- ▶ Provide a reference point against which progress can be measured
- ▶ Sometimes known as a benchmark



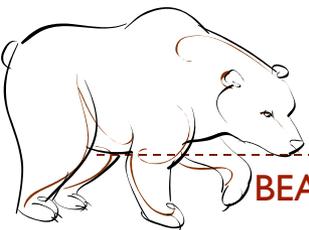
Indicators / Data Sources

- ▶ Standardized data sources are best
 - ▶ Helps legitimize any findings
 - ▶ Reduces extra surveillance work
 - ▶ Can provide a baseline
 - ▶ Examples include:
 - ▶ BRFSS, YRBS, RPMS, Vital Statistics, etc.



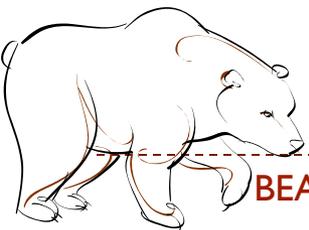
Limitations with Secondary Data Sources (GLITEC CHP, 2010)

- ▶ Racial misidentification/ “other” category
- ▶ Excluded from analysis or data collection
- ▶ Commonly under-samples/ not oversampled
- ▶ Funding



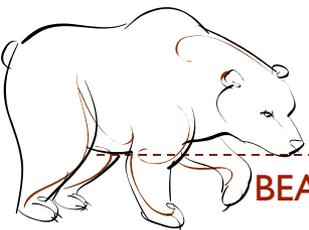
Secondary Data Source Example (GLITEC CHP, 2010)

- ▶ According to BRFSS, when asked how often they felt they received social and emotional support, 42.8 percent of American Indian/Alaska Natives..... reported always receiving social and emotional support.... This estimate was based on five-years of aggregate data with a yearly “n” of 198.
- ▶ Although a number of questions related to mental health (i.e. have you felt nervous, depressed, hopeless, etc.) issues were included, on average only six American Indian/Alaska Nativesanswered these questions each year!



Solution to Limitations with American Indian/Alaska Native Secondary Data Sources

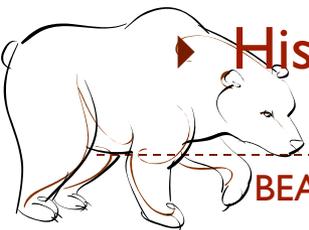
- ▶ **Collect your own primary data!**
 - ▶ **Use an already developed instrument/ tool**
 - ▶ ‘kinks’ have been ironed out (pilot testing/ norming)
 - ▶ **Create your own instrument/ tool as a last resort only!**
 - ▶ Work with your epidemiologist and/or evaluator to create this
 - ▶ Will need to pilot test prior to using for “true” data collection



Limitations with Primary Data (GLITEC CHP, 2010)

- ▶ It is sometimes difficult to collect data in Tribal communities for various reasons
 - ▶ As in all smaller communities, sampling is generally more difficult than in larger communities. For statistical validity a larger proportion of population must be sampled.
 - ▶ Participant fatigue / disinterest
 - ▶ Lack of a surveillance system coupled with inconsistent data sharing/storage policies

▶ Historical trauma



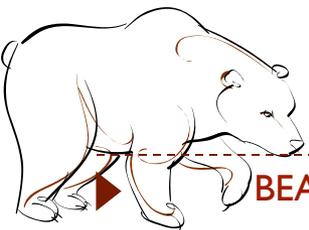
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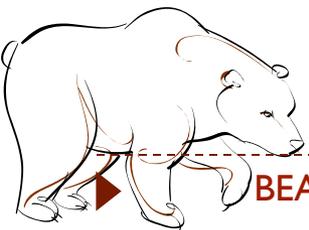
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Data Collection Methods

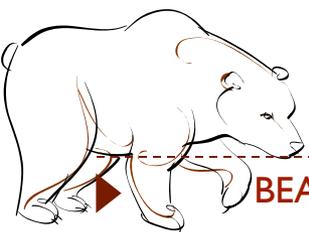
Method	Overall Purpose	Advantages	Challenges
Case studies	To fully understand or depict client's experiences in a program, and conduct comprehensive examination through cross comparison of cases	Fully depicts client's experience in program input, process and results Powerful means to portray program to outsiders	Usually quite time consuming to collect, organize and describe Represents depth of information rather than breath



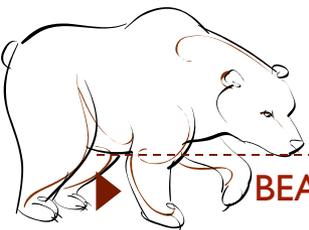
Method	Overall Purpose	Advantages	Challenges
Documentation review	When want impression of how program operates without interrupting the program; is from review of applications, finances, memos, minutes, etc.	<p>Get comprehensive and historical information</p> <p>Doesn't interrupt program or client's routing in program</p> <p>Information already exists</p> <p>Few biases about information</p>	<p>Often takes much time</p> <p>Info may be incomplete</p> <p>Need to be quite clear about what looking for</p> <p>Not flexible means to get data; data restricted to what already exists</p>



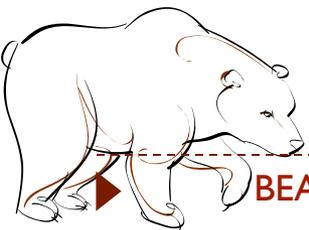
Method	Overall Purpose	Advantages	Challenges
Focus groups	Explore a topic in depth through group discussion (e.g., about reactions to an experience or suggestion, understanding common complaints, etc.); useful in evaluation and marketing	<p>Quickly and reliably get common impressions</p> <p>Can be efficient way to get much range and depth of information in short time</p> <p>Can convey key information about programs</p>	<p>Can be hard to analyze responses</p> <p>Need good facilitator for safety and closure</p> <p>Difficult to schedule 6-8 people together</p>



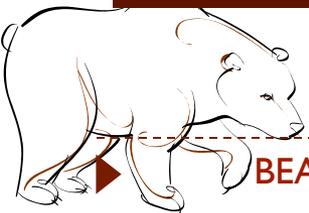
Method	Overall Purpose	Advantages	Challenges
Interview	When want to fully understand someone's impressions or experiences, or learn more about their answers to questionnaires	<p>Get full range and depth of information</p> <p>Develops relationship with client</p> <p>Can be flexible</p>	<p>Can take much time</p> <p>Can be hard to analyze and compare</p> <p>Can be costly</p> <p>Interview can bias client's responses</p>



Method	Overall Purpose	Advantages	Challenges
Observation	To gather accurate information about how a program actually operates, particularly about processes	<p>View operations of a program as they are actually occurring</p> <p>Can adapt to events as they occur</p>	<p>Can be difficult to interpret seen behaviors</p> <p>Can be complex to categorize observations</p> <p>Can influence behaviors of program participants</p> <p>Can be expensive</p>

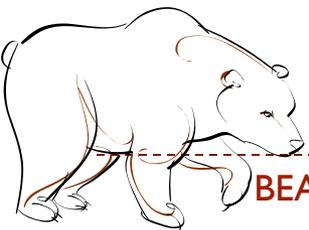


Method	Overall Purpose	Advantages	Challenges
Questionnaires, surveys, checklists	Quick and easy to get lots of information from people in a non threatening way	<p>Can complete anonymously</p> <p>Inexpensive to administer</p> <p>Easy to compare and analyze</p> <p>Administer to many people</p> <p>Can get lots of data</p> <p>Many sample questionnaires already exist</p>	<p>Might not get careful feedback</p> <p>Wording can bias client's responses</p> <p>Are impersonal</p> <p>May need sampling expert</p> <p>Doesn't get full story</p>



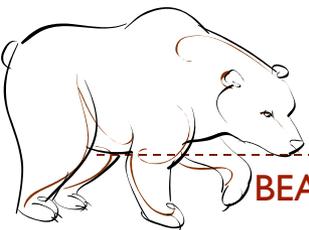
Data Handling

- ▶ Organization!
 - ▶ Don't just randomly give your epidemiologist/evaluator papers
 - ▶ Make timelines and checklists for yourself
- ▶ Data Entry/Analysis
 - ▶ Consistency
 - ▶ Pay attention



Data Handling, Continued

- ▶ Data Storage/Sharing
 - ▶ Hard copies filed away
 - ▶ Back up electronic copies
 - ▶ Be secure to insure privacy
- ▶ Make sure you've complied with the ownership, control, access, and possession agreements that had been established at the beginning of the process



A FINAL THOUGHT ABOUT DATA COLLECTION

Garbage In= Garbage Out



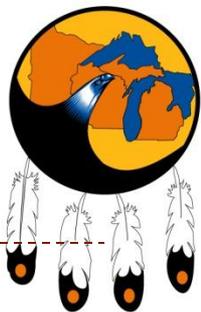
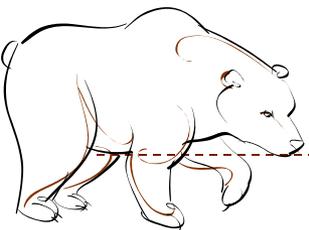
Data Analysis / Interpretation

Data Analysis:

- ▶ a process of gathering, modeling, and transforming data with the goal of highlighting useful information, suggesting conclusions, and supporting decision making

Data Interpretation:

- ▶ figuring out what your data “mean” in layman’s terms



Basic Data Analysis

▶ Basic Descriptive Statistics

▶ **Frequency** - a fancy way of saying “count”

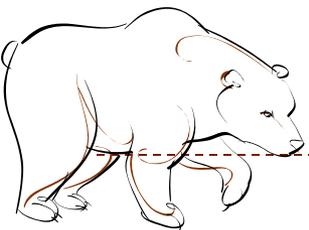
▶ Ex. Number of people attending our webinar

▶ **Percentage/Rate** - a proportion in relation to a whole (or larger group)

▶ Ex. Percent of people attending our webinar who are female

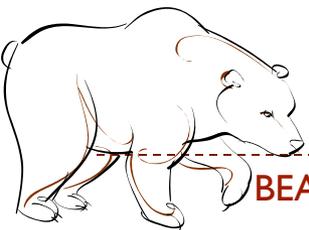
▶ **Average** - the sum of all measurements in a group divided by the number of measurements in a group

▶ Ex. Average age of people attending our presentation



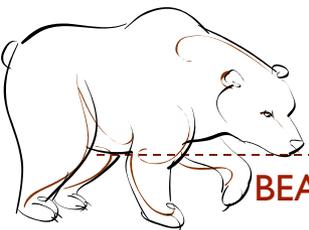
Reporting

- ▶ Reflect back to your stakeholders
 - ▶ Different versions of reports for different stakeholders
 - ▶ Make it easy to read
 - ▶ Text
 - ▶ Visuals
 - ▶ Headers
 - ▶ Consistency



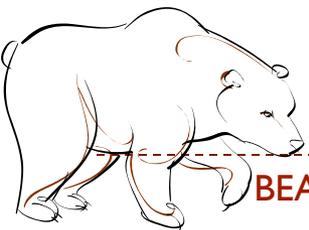
Additional Considerations

- ▶ Engage in strategic planning
- ▶ Create and follow a logic model – visual that representation can guide your if your project/program
- ▶ Make goals/objectives/actions S.M.A.R.T.E.R.
 - ▶ Specific
 - ▶ Measureable
 - ▶ Relevant
 - ▶ Time-framed
 - ▶ Extending
 - ▶ Reviewed



Additional Considerations, Continued

- ▶ **K.I.S.S. –ing is Great**
 - ▶ **Keep**
 - ▶ **It**
 - ▶ **Simple**
 - ▶ **Stupid**



References

- ▶ Community Health Data Profile: Michigan, Minnesota, and Wisconsin Tribal Communities, 2010. Great Lakes Inter-Tribal Epidemiology Center, Great Lakes Inter-Tribal Council, Inc. 2011

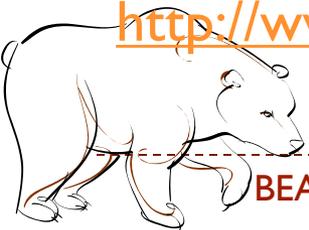
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- ▶ First Nations Centre. (2007). OCAP: Ownership, Control, Access and Possession. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization.

<http://cahr.uvic.ca/nearbc/documents/2009/FNC-OCAP.pdf>

- ▶ Pearson, 2009. *Strengthening Indian Country Through Tribal Youth Programs*, American Youth Policy Forum with the Office of Juvenile Justice and Delinquency Prevention U.S. Department of Justice.

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Questions / Comments???