



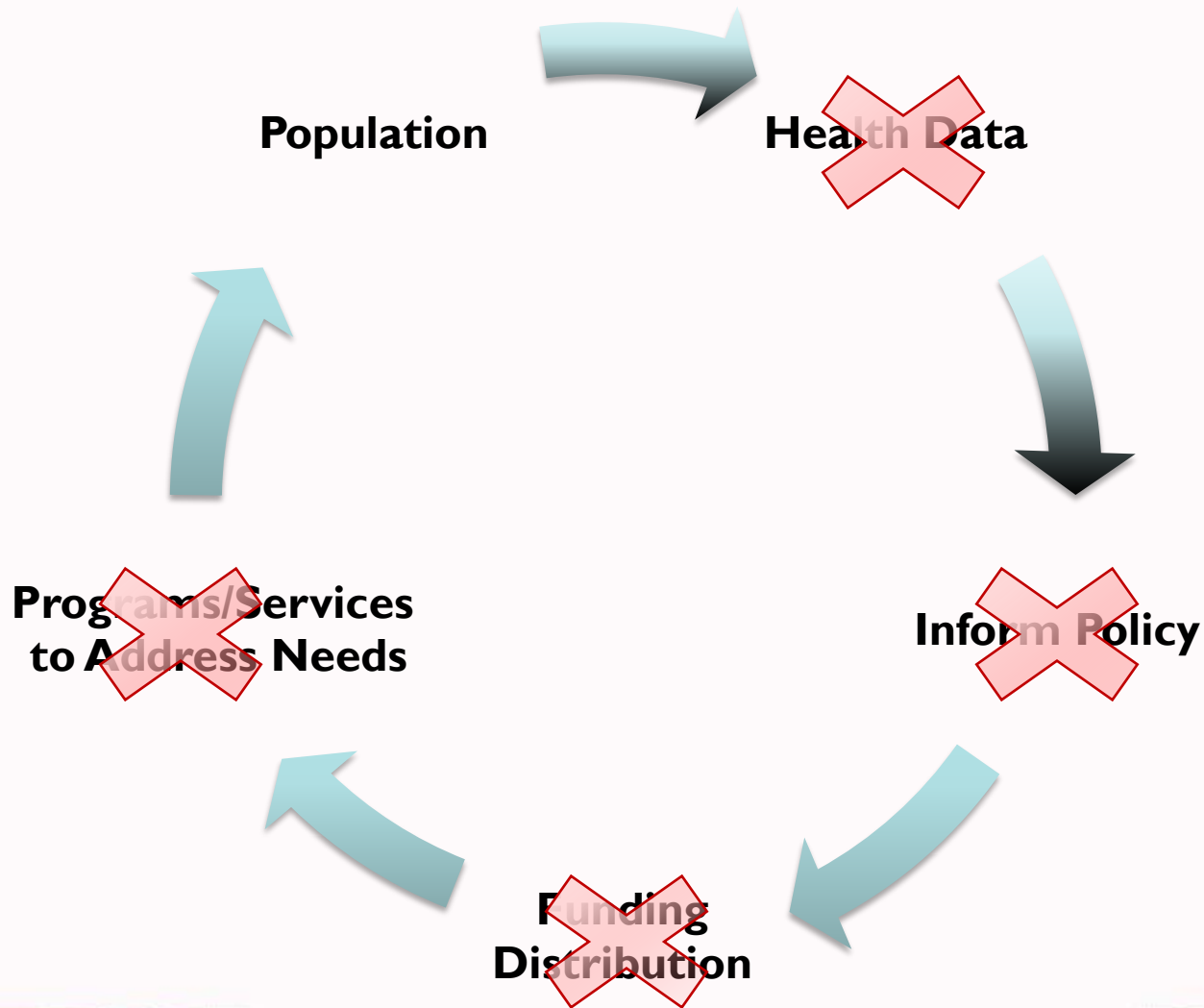
Local and National Data Needs and Challenges

**Urban Indian Health Institute, Seattle Indian Health Board, P.O. Box 3364, Seattle, WA 98114
Tel: (206) 812-3030 Website: www.uihi.org**

Background on Problem

- Lack of Standardized Data on the Health and Well-Being of Urban Indians
- Without Adequate Data
 - Remain Invisible
 - Remain Silenced
 - Continue to Experience Health Disparities
 - Diminished Power to Incite Positive Change
 - Limited Documentation on the Effectiveness of Services

Advocacy –Information Cycle



No Data \neq No Problem



**Lack of Quality Data Can
Silence A Community**

Healthy People 2010 Objectives *Visibility Through Data Report*



Types of Data

- Population

- Birth Records
- Death Records
- Reportable Diseases
- Government Surveys
- Disease Prevalence
 - Survey Respondents
 - Death Certificates

- Organization

- Medical Conditions
- Diagnosis
- Program Outcomes
- Quality Assurance
- Disease Prevalence
 - Among Patients



Urban AI/AN Population Data

Sources of Data: UIHI Analysis

Dataset:

Goals:

Vital Statistics	Identify mortality rates, deaths by specific diseases, and maternal and infant risk factors through analysis of birth and death records
BRFSS	Identify information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury for urban AI/ANs in service areas
NSFG	Examine unintended pregnancy and its correlates among AI/AN women, as compared to non-AIAN women
PRAMS	Examine stressful life events and social support among AI/AN pregnant women in WA and OR
YRBS	Describe prevalence of health risk behaviors in urban AI/AN youth Identify disparities in health risk behaviors between urban AI/AN and white youth
Birth & Death files (PPOR)	Identify the periods of risk with the most deaths and highest rates among AI/AN in WA, OR, ID

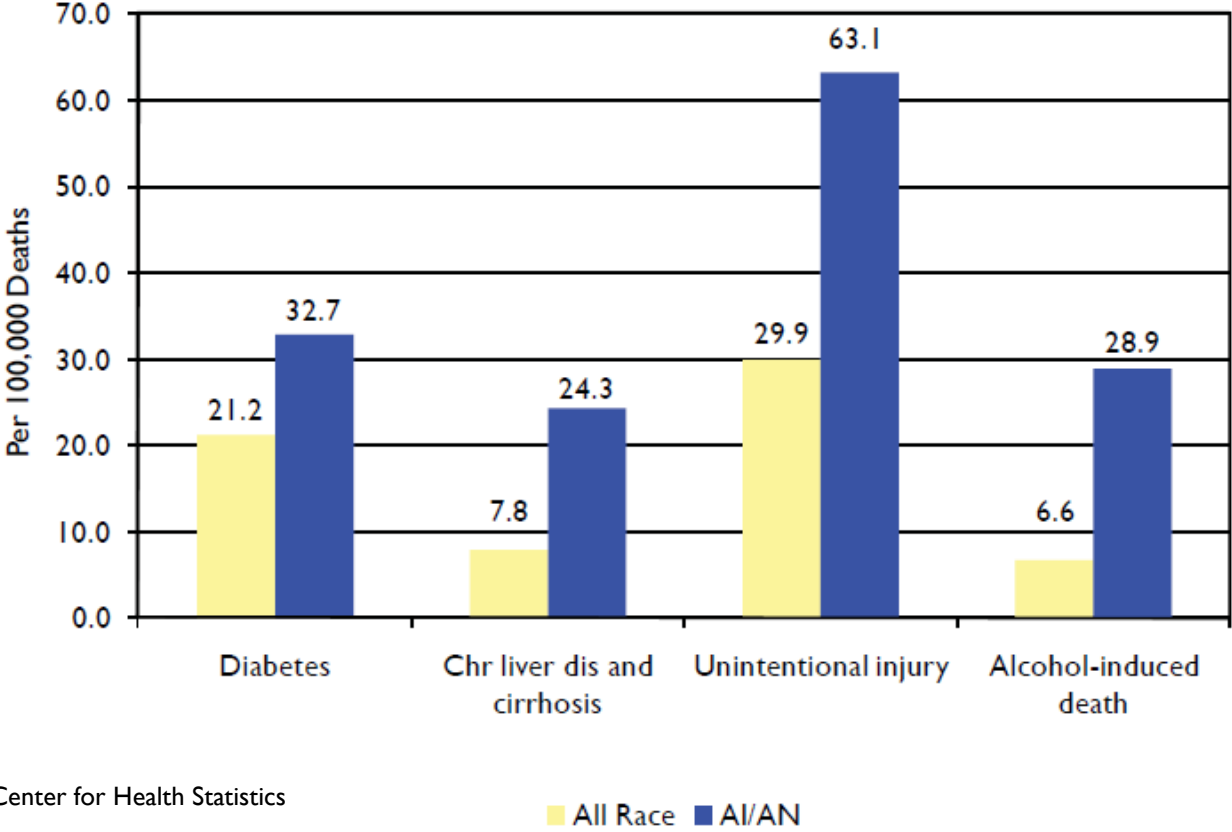
Data Collection: NCHS Vital Statistics

- Collects birth and death statistics
- Birth certificate data completed by parent
- Death certificate data completed by third party

Local File Number		Washington State Certificate of Death				State File Number	
1. Legal Name (Include AKA's if any) First Middle LAST Suffix					2. Death Date		
3. Sex (M/F)	4a. Age - Last Birthday	4b. Under 1 Year Months Days		4c. Under 1 Day Hours Minutes		5. Social Security Number	6. County of Death
7. Birthdate	8a. Birthplace (City, Town, or County)		8b. (State or Foreign Country)		9. Decedent's Education		
10. Was Decedent of Hispanic Origin? (Yes or No) If yes, specify.				11. Decedent's Race(s)		12. Was Decedent ever in U.S. Armed Forces?	
13a. Residence: Number and Street (e.g., 624 SE 5 th St.) (Include Apt. No.)						13b. City or Town	
13c. Residence: County	13d. Tribal Reservation Name (if applicable)		13e. State or Foreign Country		13f. Zip Code + 4	13g. Inside City Limits? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk	
14. Estimated length of time at residence.		15. Marital Status at Time of Death		16. Surviving Spouse's Name (Give name prior to first marriage)			
17. Usual Occupation (Indicate type of work done during most of working life. Do not use acronym)				18. Kind of Business/Industry (Do not use Company Name)			

NCHS Vital Statistics: *Seattle Indian Health Board Service Area*

Figure 9. Select Mortality Disparities, 2001-2005



Source: National Center for Health Statistics



Limitations

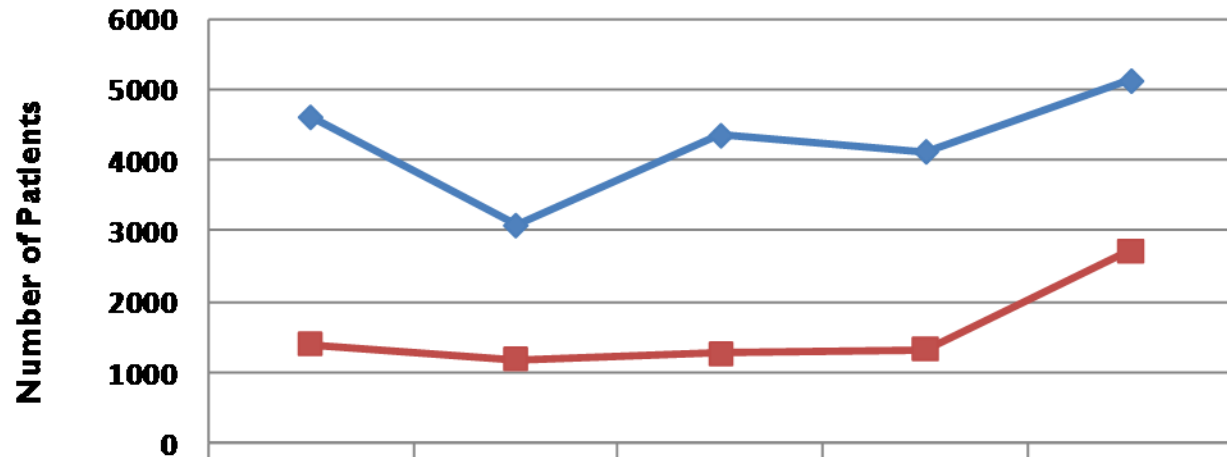
- Death Certificate Racial Misclassification
 - *45% AI/AN racially misclassified*
 - *Percentage was even higher for those in urban areas*
- Small Samples Not Reported
 - *Important indicators cannot always be presented for certain geographical areas*



Organizational Data

Diabetes

Patients in UIHO Diabetes Registries By Year



	YEAR 2004	YEAR 2005	YEAR 2006	YEAR 2007	YEAR 2008
Total number in Registries*	4614	3093	4355	4129	5123
Number of Patients Audited^	1408	1192	1278	1335	2725
Percent of Patients Audited+	31%	39%	29%	32%	53%
Number of Participating UIHO#	22	21	23	24	32

*Sum of all patients in each registry

^Sum of all patients reviewed by each site

+Number of patients audited/number of patients in registry

#Number of urban Indian health organizations participating

Table 2. Vital Statistics of Audited Patients with Diabetes, 2004-2008										
UIHO Aggregate										
Year	2004		2005		2006		2007		2008	
No. charts audited	1,408		1,192		1,278		1,335		2,725	
	No.	% ⁺	No.	% ⁺	No.	% ⁺	No.	% ⁺	No.	% ⁺
Body Mass Index (BMI)*										
< 25	114	9%	99	9%	84	6%	89	7%	202	7%
25 - 29	329	24%	259	22%	281	23%	303	23%	574	21%
≥ 30	883	62%	794	67%	874	69%	910	68%	1879	68%
Missing	82	5%	40	3%	39	2%	33	1%	70	3%
Mean BMI ⁺	34.0		34.2		34.7		34.4		34.8	
Hypertension [^]										
Yes	838	67%	800	70%	850	70%	941	74%	2038	74%
No	521	27%	367	27%	415	28%	390	26%	675	26%
Missing	49	5%	25	3%	13	1%	4	0.1%	12	1%
Blood pressure (mmHg)										
<120/<70	86	6%	112	8%	103	8%	110	8%	259	8%
120/70 - <130/<80	393	29%	387	35%	389	31%	404	33%	780	28%
130/80 - <140/<90	425	32%	351	31%	404	35%	376	28%	726	29%
140/90 - <160/<95	213	17%	143	13%	146	11%	155	13%	331	14%
160+/95+	75	5%	42	4%	36	3%	50	4%	80	3%
Missing	216	10%	157	10%	200	12%	240	14%	549	18%
Mean Systolic ⁺	130		128		128		127		128	
Mean Diastolic ⁺	79		77		77		77		77	

+Weighted estimate

*Weight in kilograms/(height in meters)²; normal < 25, overweight 25-29, obese ≥30

[^]Documented diagnosis or taking prescription medication



Table 3. Exams in Past Year among Audited Patients with Diabetes, 2004-2008

UIHO Aggregate

Year	2004		2005		2006		2007		2008	
No. charts audited	1,408		1,192		1,278		1,335		2,725	
	No.	% ⁺	No.	% ⁺	No.	% ⁺	No.	% ⁺	No.	% ⁺
Eye Exam										
Yes	672	54%	630	52%	585	49%	642	50%	1339	48%
No	686	42%	495	41%	618	45%	676	49%	1330	49%
Refused	41	3%	63	7%	64	5%	17	1%	41	2%
Missing	9	1.0%	4	0.3%	11	1.1%	0	0%	15	0.8%
Foot Exam										
Yes	845	67%	760	64%	843	68%	903	68%	1854	68%
No	544	31%	401	32%	390	28%	415	31%	849	31%
Refused	12	1%	28	3%	39	3%	15	0.7%	13	0.5%
Missing	7	0.9%	3	0.2%	6	0.6%	2	0.1%	9	0.6%
Dental Exam										
Yes	372	26%	350	30%	399	28%	418	26%	784	27%
No	975	70%	771	63%	798	66%	892	73%	1847	69%
Refused	52	3%	64	7%	71	5%	24	1%	70	3%
Missing	9	0.9%	7	0.7%	10	1.0%	1	0.0%	24	1.3%

+Weighted estimate

Organizational Data

- Program Assessment
- Outcomes and Quality Improvement
- Prevalence Rates in Patient Population
- Accurate Racial Classification
- Accurate Health Status

Beyond Diabetes....

No National Urban Indian Health Organization Data

- *Example: The national rate of infant death from SIDS among urban AI/AN is 2 ½ times that of all races combined.*

While local information is not available, this is consistent with what we have seen recently in our own community with the known death of two babies from SIDS within the past year.



Propose and Discuss Solutions