Northwest Tribal Registry Data Assessment – One-page Summary

IDEA-NW/Tribal Registry Project, NPAIHB

June, 2012

The purpose of this evaluation was to assess the representativeness of the Northwest Tribal Registry, ninth version (NTR9). The NTR is used routinely for record linkages with various health-related surveillance systems (e.g., cancer registries and death certificates) to identify and correct AI/AN racial misclassification. We wished to assess how well this data source represented the AI/AN resident population of Idaho, Oregon, and Washington; and to identify sub-populations that may be targeted for inclusion in order to provide the most accurate health status data for all Northwest AI/ANs.

The NTR9 was created in June, 2011 from a combination of 3 source data sets:

- Portland Area IHS Area-wide Patient Registration File, obtained 04/20/2011 (all patients ever registered at a clinic that was on RPMS at the time of the data pull, and to which the Area Office had direct access)
- Seattle Indian Health Board patient registration (AI/AN patients registered 01/01/2007 – 05/31/2011)
- Patient registration file from one Washington tribe. This clinic does not use RPMS, thus data from these patients were not available through the Area Office (active patients as of 06/23/2011)

Comparison data sources

- Bridged-race population estimates, 2009, from CDC/NCHS (primary source used)
- U.S. Census intercensal population estimates of AI/AN race alone, 2009
- American Community Survey, 2009 population estimates of AI/AN race alone (for urban population measures)
- 2011 Indian Health Service (IHS) User Population numbers by service unit

<u>Key findings</u>

- Among data elements important to this evaluation and to record linkage activities, missing data were relatively rare. Over 90% of records were found to be residents of Idaho, Oregon, or Washington. There were proportionally slightly more females in the NTR9 (51.5%) compared to NCHS population estimates (49.5% of AI/AN Northwest population).
- Proportionally, 76.2% of the Northwest NCHS AI/AN population estimate was represented in the NTR9. Statewide, Oregon AI/ANs appeared to be the least well represented (66% of NCHS estimate represented in NTR9), followed by Idaho (79%) and Washington (81%).
- Younger age groups – most notably children ages 0-9 – were severely under-represented (ratio = 0.37). This indicates that linkages with data systems containing substantial numbers of children (e.g., childhood disease registries or hospitalization data) will less completely identify AI/AN racial misclassification. Most adult age groups (ages 20-79) were proportionally similar to census-based age distributions.
- The NTR9 does not equally represent all tribes/service units in the Northwest; several appear to be represented fairly well (close to 100%), while others are represented very little or not at all.
- Some CHSDA counties were less well represented, which may be correlated with characteristics of health system delivery for that tribe/area, such as lack of an I/T/U facility or a tribal clinic not using RPMS.
- The NTR9 under-represented urban AI/AN populations on the whole, but in some cities the NTR9 populations closely approximated ACS estimates (e.g., Idaho Falls, Pocatello, Pendleton-Hermiston, and Bellingham). The three cities with urban Indian clinics remained under-represented: only 33.6% of the Portland-Vancouver-Beaverton area population was captured in the NTR9, while for Seattle-Bellevue-Tacoma and Spokane the estimates were 47.1% and 66.5%, respectively.
- As expected, the NTR9 better represented AI/ANs in CHSDA areas than non-CHSDA counties, rural areas compared with urban areas, and tribal and IHS service populations where there is an RPMS-reporting clinic. These findings are consistent with the sources of our data.

For more information, please see the full NTR9 Evaluation Report, http://www.npaihb.org/epicenter/project/reports/

Contact: IDEA-NW/Tribal Registry Project • NPAIHB • ideanw@npaihb.org

Tribe/Service Unit Population Comparisons

NTR9 = Ninth version, Northwest Tribal Registry

TRIBE/SERVICE UNIT	Included in IHS registration export? (as of April, 2011)	On RPMS?	UserPop FY2011	NTR9 - Tribe*	Percent of User Pop represented	CHSDA population estimate (NCHS)	NTR9 CHSDA population – county of residence**	Percent of CHSDA pop represented
Burns Paiute	Yes	Yes	215	260	**122.6%**	388	441	113.7%
Chehalis	Yes	Yes	1,245	558	**46.7%**	10,452	7,852	75.1%
Coeur d'Alene	No	No	5,014	435	**9.0%**	12,945	6,543	50.5%
Colville	Yes	Yes	8,384	7,522	**90.7%**	13,034	14,774	113.3%
Coos, Lower Umpqua, Siuslaw	Yes	No	778	524	**67.9%**	12,363	7,604	61.5%
Coquille	Yes	No	1,163	518	**48.5%**	13,152	5,733	43.6%
Cow Creek	Yes	Yes	2,580	1,084	**45.6%**	19,826	11,303	57.0%
Cowlitz	Yes	Yes	2,422	1,823	**77.8%**	52,271	35,799	68.5%
Grand Ronde	Yes	No	3,703	3,709	**102.7%**	27,762	17,441	62.8%
Hoh	No	No	30	160	**484.8%**	843	214	25.4%
Jamestown	No	No	58	167	**36.4%**	5,076	5,266	103.7%
Kalispel	No	No	69	130	**28.8%**	10,142	4,593	45.3%
Klamath	No	No	2,520	1,184	**42.6%**	3,504	3,895	111.2%
Kootenai	Yes		183	145	**80.1%**	265	364	137.4%
Lower Elwha	No	Yes	856	394	**47.8%**	4,233	5,052	119.3%
Lummi	No	Yes	4,361	627	**14.2%**	6,525	5,796	88.8%
Makah	Yes	Yes	2,244	1,968	**91.4%**	4,233	5,052	119.3%
Muckleshoot	Yes	Yes	4,402	2,041	**45.4%**	37,056	29,669	80.1%
Nez Perce	Yes	Yes	3,971	2,635	**70.7%**	3,898	5,826	149.5%
Nisqually	No	Yes	1,715	170	**12.7%**	19,524	20,205	103.5%
Nooksack	Yes	Yes	1,086	1,098	**109.4%**	6,525	5,796	88.8%
NW Band of Shoshone	No	No	39	112	**339.4%**	0	0	0.0%
Port Gamble	No	No	1,531	102	**6.4%**	4,827	2,281	47.3%
Puyallup	No	No	7,773	2,524	**32.3%**	41,945	32,166	76.7%
Quileute	Yes	Yes	674	610	**91.6%**	5,076	5,266	103.7%
Quinault	Yes	Yes	2,511	2,671	**106.8%**	5,120	4,862	95.0%
Samish	Yes	Yes	593	594	**104.0%**	69,464	54,428	78.4%
Sauk-Suiattle	Yes	Yes	48	128	**200.0%**	14,935	11,156	74.7%
Shoalwater Bay	Yes	Yes	419	127	**29.3%**	690	805	116.7%
Shoshone Bannock	Yes	Yes	6,271	4,603	**73.5%**	6,692	9,412	140.6%
Siletz	Yes	Yes	5,207	3,926	**75.9%**	42,703	26,114	61.2%
Skokomish	Yes	Yes	853	726	**94.0%**	2,650	2,492	94.0%
Snoqualmie	Yes	Yes	249	307	**100.0%**	52,780	40,911	77.5%
Spokane	Yes	Yes	1,628	1,898	**115.9%**	4,521	6,260	138.5%
Squaxin Island	Yes	Yes	795	814	**100.0%**	2,650	2,492	94.0%
Stillaguamish	Yes	Yes	125	145	**97.3%**	12,178	8,551	70.2%
Suquamish	No	No	542	98	**17.8%**	4,827	2,281	47.3%
Swinomish	Yes	Yes	1,233	816	**65.4%**	2,757	2,605	94.5%
Tulalip	Yes	Yes	5,021	3,670	**75.2%**	12,178	8,551	70.2%
Umatilla	Yes	Yes	3,066	1,730	**56.9%**	3,185	2,758	86.6%
Upper Skagit	Yes	Yes	517	642	**118.9%**	2,757	2,605	94.5%
Warm Springs	Yes	Yes	5,669	4,731	**84.1%**	18,807	16,216	86.2%
Western Oregon Service Unit	Yes	Yes	2,790	-	**-**	-	-	-
Yakama	Yes	Yes	12,629	6,565	**52.4%**	15,973	18,918	118.4%
NARA	No	Yes	-	-	**-**	-	-	-
SIHB	No	No	-	-	**-**	-	-	-
Spokane Urban Clinic	No	Yes	-	-	**-**	-	-	-
TOTAL			**107,182**	64,691	**60.8%**	**N/A; regions overlap**	**N/A; regions overlap**	**N/A; regions overlap**

* Alive residents of ID, OR, or WA; restricted to date of last update 1/1/2008 or later

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