Northwest Tribal Registry, 9th version (NTR9) Data Assessment

IDEA-NW Project June 2012



Northwest Portland Area Indían Health Board



### BACKGROUND



Since 1999, the Northwest Tribal Registry Project has worked to identify and reduce racial misclassification of American Indians/Alaska Natives (AI/AN) in a range of public health data systems through record linkage studies with the Northwest Tribal Registry (NTR). The goal of this effort is to provide morbidity and mortality data of improved completeness and quality for the Northwest AI/AN population. The Improving Data & Enhancing Access (IDEA-NW) Project is an extension of this effort, working to expand the completeness and quality of AI/AN race data in data systems across the Northwest, and providing local-level data to inform tribal health decision-making.

The quality and usefulness of the information obtained from record linkages depends on the accuracy, completeness and representativeness of the data sets used. If the NTR is not complete or representative of the Northwest AI/AN population as a whole, record linkage studies may not yield accurate or valid conclusions. The NTR was evaluated for completeness and representativeness in 2003 (NTR4, or the fourth iteration of the data set), but it has not undergone a thorough assessment since. At that time, it was estimated that the number of registrants in the NTR represented about 73% of the Northwest AI/AN Census population. This report also found that the NTR4 had a slightly younger age distribution than Census-based population estimates, and that it under-represented AI/AN populations in urban areas (particularly King County, WA).

The purpose of this analysis is to re-assess the completeness and representativeness of the current version of the NTR (NTR9, the ninth iteration) and the population contained therein. In doing so, we hope to provide a level of confidence in the conclusions drawn from linkage studies about the health status of Northwest AI/ANs.

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## NORTHWEST TRIBAL REGISTRY DATA SET

Northwest AI/ANs receive health care services from a wide variety of providers. The Indian health care delivery system in the Northwest is comprised of a combination of Indian Health Service (IHS) direct service clinics, tribally operated programs, and three urban Indian clinics (collectively referred to as I/T/U programs). In general, to be eligible for services at I/T/U facilities, an individual must provide documentation of AI/AN descent (usually tribal enrollment) and, to access contract health services, belong to the AI/AN community served by the local facility. Additionally, non-AI/AN women pregnant with an eligible AI/AN's child may be eligible for services (only during the period of her pregnancy through postpartum), as well as non-AI/AN members of an eligible AI/AN's household if it is determined by the medical officer in charge that their illness requires treatment to control an acute infectious disease or public health hazard.

The majority of these Northwest Indian health care facilities utilize the Indian Health Service's (IHS) computerized health information system called the Resource and Patient Management System (RPMS). These health care facilities routinely export patient data to the Portland Area IHS office (covering Idaho, Oregon and Washington) and demographic data elements are automatically entered into a composite file known as the Portland Area IHS Area-wide Patient Registration File. Health care facilities that do not employ RPMS may or may not report demographic and diagnostic data to the Portland Area IHS Office. Some tribal programs have recently moved from using RPMS to other health information systems (e.g., NextGen), resulting in their patient registration data not being collected routinely by the Portland Area IHS Office.

As authorized through Northwest Portland Area Indian Health Board (NPAIHB) resolution, the NPAIHB has a data sharing agreement with the Portland Area IHS Office to obtain demographic data on all registrants contained in the IHS Area-wide Patient Registration File. A new copy of this data set is requested from the Portland Area Office approximately every 12-18 months. The Area-wide Patient Registration File contains information on all individuals who have ever registered at a reporting IHS, tribal, or urban clinic site in the Northwest; it is not limited to live individuals or active patients. Thus some patients may have a registration date as early as the mid-1980s, but most have been registered or updated more recently (85% registered between 2000 and 2011). The specific data elements that are obtained include personal identifying information sufficient to determine Indian status for IHS eligibility and to distinguish the same individual across multiple data systems (e.g., full name, date of birth, social security number, race, sex, address, tribe, Indian blood quantum, classification/beneficiary code, and facility)<sup>1</sup>.

<sup>1</sup> Indian Health Service. Indian Health Manual, Part 2 Chapter 6: Patient Registration System. Available at: <u>http://www.ihs.gov/ihm/index.cfm</u>





There are limitations in using the IHS Area-wide Patient Registration File to approximate the total AI/AN population of Idaho, Oregon, and Washington. These include:

- Not all Northwest AI/ANs access (or eligible for) care at I/T/U facilities
- Not all I/T/U facilities report their registration doata to the IHS Area Office (e.g., clinics not using RPMS)
- Not all Northwest tribes have a local clinic
- The same individual may be registered at more than one facility, resulting in multiple records for that person

Throughout the Registry Project's history, the NTR data set has, at times, been supplemented by other lists of Northwest AI/ANs, such as tribal enrollment lists, tribal clinic registration data, and urban clinic patient registration data. These

special arrangements have been made through written agreements (and/or resolution) with individual tribes, tribal programs, or urban facilities as appropriate. In general, this approach has supplemented the NTR data for a specified period of time, but these additional data sources have not become permanent additions to the NTR. Through a data sharing agreement with the Seattle Indian Health Board, we have included their urban clinic patient registration data annually since 2008.

## **METHODS**

#### Preparation of NTR9 Linkage Data Set

The ninth version of the Northwest Tribal Registry (NTR9) included the following data sources:

- Portland Area IHS Area-wide Patient Registration Flie, obtained 04/20/211 (all patients ever registered), N=220,342
- Seattle Indian health Board patient registration, obtained 06/15/2011 (AI/AN patients registered 01/01/2007 05/31/2011), N=9,514
- Patient Registraion file from one Washington tribe. This clinic does not use RPMS, thus data from these patients are not available through the Area Office (active patients as of 06/23/2011), N=12,276

The first step to creating the NTR9 Linkage Data Set was to thoroughly clean all data fields and delete nonsense or "dummy" records. We then restricted the data set to AI/AN registrants using several fields for which "Indian Status" can be assessed (Indian blood quantum, tribe of enrollment/affiliation, and classification (an RPMS-specific designation)). All non-AI/AN records and records for which race could not be determined were removed. The size of the data set after this step was 179,231 AI/AN records.

Additionally, we added a subset of records from NTR8 from facilities that had previously reported registration data to the Area Office but did not provide an update in 2011. These facilities included Benewah Medical Center, Klamath, Lower Elwha, Lummi Tribal Health, Neah Bay, Nisqually, North Idaho, NW Band of Shoshone, Port Gamble, Puyallup, Spokane Urban Clinic, Suquamish, and Taholah Health Clinic. The size of the data set after this step was 210,981 AI/AN records.



We then de-duplicated the cleaned IHS registration data through a probabilistic linkage process using Link Plus software. If we were uncertain whether two records represented the same individual, we erred on the side of calling them NON-matches to maximize the number of unique records in the data set, which in turn would provide increased likelihood of identifying matches with external data sources (e.g., when NTR is matched with the cancer registry). Duplicate records were removed through an algorithm chosen to maximize the possibility of matching with external data sources (e.g., if one record contained a full SSN, it was kept preferentially over its duplicate which contained only the last 4 digits of SSN). At the end of this de-duplication process we were left with 194,413 records.

Each additional data source was then added to the IHS list through a probabilistic matching process. One record was retained from each matched pair, using the same algorithm mentioned above to maximize useful linkage data fields, while weighting the "added" record heavier (i.e., preferentially keeping the tribal clinic or SIHB record over the IHS record, unless the "added" record had a lot of missing data). We added a "flag" variable to indicate the source(s) of each record. Again, uncertain matches were handled by erring on the side of calling them non-matches for the purpose of increasing match opportunities with outside data sets. The size of the linkage data set at this point was 208,783 records. Of these, 89.6% came from the IHS file alone, 5.9% from the tribal clinic alone, 3.2% from SIHB alone, and 1.4% were contained in two or more source files.

#### Preparation of NTR9 Evaluation Data Set

The objective of the current evaluation analysis is to compare the NTR9 with the Northwest AI/AN population to assess the completeness and representativeness of the NTR9. To most accurately accomplish this, the data set needed to be de-duplicated as completely as possible to one record per individual, and also have some indication of which individuals were alive as of a given date. We thus created a separate version of the NTR9 to evaluate, called NTR9 Evaluation Data Set.

The IHS registration data contains a date of death field, but it was unknown how completely and consistently it was updated for deceased patients. The tribal clinic registration data also included this field – again, of unknown quality. The SIHB patient data did not have any date of death information. We had recently completed record linkages of NTR9 data with death certificate data from Washington (through 2009) and Oregon (through 2010), so we had some supplemental information for matched records. We thus included a flag to indicate NTR9 records that were known to be deceased from any of these four sources: date of death indicated in IHS record, date of death indicated in tribal registration record, match with Washington death certificate (deceased as of 12/31/2009), and match with Oregon death certificate (deceased as of 12/31/2010). Unfortunately, we did not retain an identifier to link date of death from the Oregon linkage back to the NTR9 record, so we couldn't tell which records were deceased as of 2009 to maintain consistency with Washington results. Additionally, we did not have any supplemental death information for Idaho residents. All records not known to be deceased were presumed alive for the purposes of analysis.

This file was then de-duplicated again, more aggressively than previously described. If we were uncertain whether two records represented the same individual but there was some evidence supporting it, we erred on the side of calling them matches, in an effort to remove all duplicate records. For matched pairs, we retained the record with the most recent date of last update, assuming that residence, clinic, and tribal affiliation information would be the most current and accurate through this method.





None of the data sources contributing to NTR9 contained county of residence, but we did have address information for most registrants. We used datasets found online (http://www.corragroup.com/zip-code-lookup.html) to map zip codes to counties in the three Northwest states. Where a single zip code mapped to more than one county, we tried to select the most populated county for that record. However, we did not spend much time validating the accuracy of these data sets, and the use of zip codes to determine other geographic units of residence is known to be a faulty method; as a result, county-level comparisons should be

interpreted with caution.

The final NTR9 Evaluation Data Set contained 203,232 records. Because all data had been previously deduplicated at least twice using different parameters to retain matches, the number of records from each source (IHS, tribal clinic, and SIHB; see Table 1) does not necessarily represent that source's original contribution to the data set. However, the proportional distribution of records by source was similar between the NTR9 Linkage File and the NTR9 Evaluation Data Set.

#### **Comparison data sources**

The primary data source chosen for comparison was the CDC/NCHS 2009 bridged-race population estimates for Idaho, Oregon and Washington by race, age, sex, and county<sup>2</sup>. These estimates are based on U.S. Census enumerations, and represent a population count that takes into account individuals who self-select more than one race on the U.S. Census form, by "bridging" each multi-race respondent into a single race category. They can be viewed as a demographically-adjusted "average" of single-race counts and multiple-race counts. This data source was used to evaluate the NTR9 at state and county levels, and age and sex distributions.

For state-level comparisons, we also present intercensal estimates of the AI/AN alone population released by the U.S. Census Bureau<sup>3</sup>. These provide estimates for years between decennial census counts of the resident population who reports only one race. For urban population comparisons, we used AI/AN alone population estimates obtained from the 2009 American Community Survey (ACS)<sup>4</sup>. ACS population data for single race groups are available down to metropolitan and micropolitan area levels, thus we used this data source to evaluate the urban NTR9 population. However, the ACS is designed to provide demographic, social, economic, and housing data at the community level, not to provide reliable population estimates between census years; thus population comparisons using this data source should be interpreted with caution.

Finally, we used 2010 IHS User Population estimates for Portland Area tribes released by the IHS. These represent unduplicated counts of AI/AN registrants by residence who have had direct encounters with, or contracted for, IHS inpatient, ambulatory, or dental services during the last three years. This data source was used to evaluate NTR9 counts and distributions by service unit.

<sup>&</sup>lt;sup>2</sup> National Center for Health Statistics. Postcensal bridged race population estimates. http://www.cdc.gov/nchs/nvss/bridged\_race.htm

<sup>&</sup>lt;sup>3</sup> U.S. Census Bureau. Intercensal population estimates by state. http://www.census.gov/popest/data/intercensal/index.html

<sup>&</sup>lt;sup>4</sup> U.S. Census Bureau. American Community Survey. http://www.census.gov/acs/www/. Data obtained from Integrated Public Use Microdata Series, http://usa.ipums.org/usa/



## RESULTS

#### **General characteristics**

The final NTR9 Evaluation Data Set contained 203,232 records. Almost 95% of them were presumed to be alive for the purposes of this analysis. Approximately 90% of the records originated from the IHS Area-wide Patient Registration File alone; 5.2% were from the tribal clinic enrollment, and 3.2% from SIHB (Table 1).

Slightly more than half of the registrants were female (51.5% versus 48.5% males), and the sex distribution was similar across the three Northwest states. The majority (91%) of registrants reported their place of residence to be in one of the three Northwest states, and for just under half (46%) of those who had a principle tribe indicated, it was a Portland Area tribe. The proportion of missing data for variables of interest to this analysis was relatively small (Table 1).

Table 1. General characteristics of NTR9 Evaluation Data Set					
	Ν	%			
Total records	203,232				
Dead	11,237	5.5%			
Alive (presumed)	191,995	94.5%			
Source: (not representative of original source contribution; duplicates de	eleted)				
IHS	183,311	90.2%			
Tribal Clinic (TC)	10,528	5.2%			
SIHB	6,560	3.2%			
IHS+SIHB	2,764	1.4%			
IHS+SIHB+TC	69	0.0%			
Among alive:					
Male	93,135	48.5%			
Female	98,858	51.5%			
State of residence = ID, OR, or WA	175,174	91.2%			
Portland Area tribal affiliation (among records with a tribe indicated)	88,388	46.0%			
Missing YEAR OF BIRTH	123	0.1%			
Missing SEX	2	0.0%			
Missing STATE	3,392	1.8%			
Missing CITY	3,037	1.6%			
Missing TRIBE 9,042					
Missing COUNTY (among ID, OR, WA residents)	1,829	1.0%			
Missing YEAR OF LAST UPDATE	3,856	2.0%			





#### Comparison to state populations

Because we could not verify that individuals listed in the Registry were the same AI/AN persons enumerated in the NCHS, intercensal or ACS population estimates, the comparisons of the data sets that follow cannot be used to determine a true rate of ascertainment of the NTR with respect to the population estimates. We can only compare the respective distributions and draw inferences about the completeness and representativeness of the

NTR based on recognized similarities and differences, such as gender, age and state.

Table 2 presents NTR9 comparisons to state populations, using both NCHS bridged-race estimates and intercensal AI/AN alone (single-race) estimates. Proportionally, 76.2% of the Northwest NCHS population estimate was represented in the NTR9. These proportional distributions varied somewhat across the three Northwest states: only about 66% of the Oregon AI/AN population was represented, versus 79% in Idaho and 81% in Washington. Comparisons to the U.S. Census intercensal AI/AN single-race estimates show a similar pattern, with NTR9 proportionally representing about 84% of the Northwest AI/AN alone population.

Table 2. Northwest AI/AN population estimates by data source, 2009					
	NTR9 (alive)	NCHS Bridged- Race Population	Percent of NCHS estimate represented in NTR9	Intercensal population (Al/AN alone)	Percent of intercensal Al/AN alone estimate represented in NTR9
Idaho	20,996	26,632	78.8%	24,045	87.3%
Oregon	46,205	69,890	66.1%	64,268	71.9%
Washington	107,973	133,364	81.0%	120,167	89.9%
Northwest Total	175,174	229,886	76.2%	208,480	84.0%

#### Age and sex distributions

As shown in Figures 1 and 2, the age distribution of the NTR9 population was markedly different than NCHS Census-based population estimates. Younger age groups, particularly children ages 0-9, were underrepresented by the NTR9, and those aged 80 and older were over-represented. This is likely due to our limited ability to identify which NTR9 registrants are deceased (thus overcounting many over 80 as "alive"), and the fact that very young children may be less likely to have encounters with the I/T/U health system in the Northwest. Ratios of NTR9 to NCHS estimates were relatively close to 1.0 (ranging from 0.83 to 0.96) for ages 20-79, indicating that most adult AI/ANs were fairly well represented (Figure 2). The age distributions across all age groups were fairly consistent for males and females, with slight variations (Figure 1).









#### Comparison to tribe/service unit and county populations

Table 3 presents estimates from the NTR9 compared to User Population numbers from IHS and Contract Health Service Delivery Area (CHSDA) region population estimates from NCHS. IHS User Population numbers were compared with the Tribe field from RPMS. For this comparison we restricted to NTR9 records with date of last update in 2008 or later, to more closely approximate User Population criteria (active clinic patients with a qualifying visit within the past 3 years).

The last three columns of Table 3 present NCHS bridged-race population estimates by CHSDA (one or more counties for each tribe), compared to county of residence

data from the NTR9. This is meant to provide another estimate of the NTR's representativeness by tribe. Using both of these comparisons, it is clear that some tribes/service units were well represented, while others were represented very little or not at all. The degree of representation is correlated with whether each service unit is on RPMS, and thus, is included in the Area-wide patient data pull from IHS.

Included in IHS registration	NTR9=Ninth	version, North	west Tribal R	egistry			
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 CHSDA p represen
Yes	Yes	215	260	122.6%	388	441	113
Yes	Yes	1,245	558	46.7%	10,452	7,852	7
No	No	5,014	435	9.0%	12,945	6,543	50
Yes	Yes	8,384	7,522	90.7%	13,034	14,774	113
Yes	No	778	524	67.9%	12,363	7,604	6
Yes	No	1,163	518	48.5%	13,152	5,733	43
Yes	Yes	2,580	1,084	45.6%	19,826	11,303	5
Yes	Yes	2,422	1,823	77.8%	52,271	35,799	68
Yes	No	3,703	3,709	102.7%	27,762	17,441	62
No	No	30	160	484.8%	843	214	25
No	No	58	167	36.4%	5,076	5,266	103
No	No	69	130	28.8%	10,142	4,593	4
No	No	2,520	1,184	42.6%	3,504	3,895	11:
Yes	Yes	183	145	80.1%	265	364	137
No	Yes	856	394	47.8%	4,233	5,052	119
No	Yes	4,361	627	14.2%	6,525	5,796	88
Yes	Yes	2,244	1,968	91.4%	4,233	5,052	119
Yes	Yes	4,402	2,041	45.4%	37,056	29,669	80
Yes	Yes	3,971	2,635	70.7%	3,898	5,826	149
No	Yes	1,715	170	12.7%	19,524	20,205	103
Yes	Yes	1,086	1,098	109.4%	6,525	5,796	88
No	No	39	112	339.4%	0	0	(
No	No	1,531	102	6.4%	4,827	2,281	4
No	No	7,773	2,524	32.3%	41,945	32,166	70
Yes	Yes	674	610	91.6%	5,076	5,266	103
Yes	Yes	2,511	2,671	106.8%	5,120	4,862	9
Yes	Yes	593	594	104.0%	69,464	54,428	78
Yes	Yes	48	128	200.0%	14,935	11,156	74
Yes	Yes	419	127	29.3%	690	805	116
Yes	Yes	6,271	4,603	73.5%	6,692	9,412	140
Yes	Yes	5,207	3,926	75.9%	42,703	26,114	63
Yes	Yes	853	726	94.0%	2,650	2,492	94
Yes	Yes	249	307	100.0%	52,780	40,911	7
Yes	Yes	1,628	1,898	115.9%	4,521	6,260	138
Yes	Yes	795	814	100.0%	2,650	2,492	94
Yes	Yes	125	145	97.3%	12,178	8,551	7
No	No	542	98	17.8%	4,827	2,281	4
Yes	Yes	1,233	816	65.4%	2,757	2,605	9.
Yes	Yes	5,021	3,670	75.2%	12,178	8,551	7
Yes	Yes	3,066	1,730	56.9%	3,185	2,758	8
Yes	Yes	517	642	118.9%	2,757	2,605	94
Yes	Yes	5,669	4,731	84.1%	18,807	16,216	8
Yes	Yes	2,790	-	-	-	-	
Yes	Yes	12,629	6,565	52.4%	15,973	18,918	11
No	Yes	-	-	-	-	-	
NO	NO	-	-	-	-	-	
NO	res	-	-	-	N/A: regions	N/A: regions	N/A: reg
		107,182	64,691	60.8%	overlap	overlap	000
	Yes   Yes   No   Yes   No   No   Yes   No   Yes   No   Yes   No   Yes   Yes   No   Yes   Yes	Yes Yes   Yes Yes   No No   Yes Yes   Yes No   Yes No   Yes No   Yes No   Yes Yes   Yes Yes   Yes Yes   Yes No   No No   No No   No No   No No   No No   No Yes   Yes Yes <td>Yes Yes Yes 215   Yes Yes 1,245   No No 5,014   Yes Yes 8,384   Yes No 778   Yes No 1,163   Yes Yes 2,580   Yes Yes 2,422   Yes No 30   No No 4,361   Yes Yes Yes   Yes Yes 4,402   Yes Yes Yes   Yes Yes 1,715   Yes Yes Yes   Yes Yes 1,831   No No No   No No 1,715   Yes Yes Y</td> <td>Yes Yes 215 260   Yes Yes 1,245 558   No No 5,014 4355   Yes Yes 8,384 7,522   Yes No 1,163 518   Yes Yes 2,580 1,084   Yes Yes Yes 2,580 1,084   Yes Yes No 3,703 3,709   No No No 30 160   No No S 167   No No S 167   No No S 167   No No 2,520 1,184   Yes Yes Yes 183   No No S 3,971   Yes Yes Yes 3,971   Yes Yes Yes 3,971   Yes Yes Yes 1,021   No No No 1,023</td> <td>Yes Yes Yes 215 260 122.6%   Yes Yes 1,245 558 46.7%   No No No 778 524 67.9%   Yes No 1,163 5181 48.5%   Yes No 1,163 5181 48.5%   Yes Yes No 1,163 5181 48.5%   Yes No 3,703 3,709 102.7%   No No No 30 160 484.8%   No No No 856 130 28.8%   No No No 4,361 62.742 1,84 42.6%   Yes Yes Yes 130 28.8% 80.1% 80.1% 80.1% 80.1%   No No Yes A361 62.74 1.968 91.4%   Yes Yes Yes 1,715 170 12.7%   Yes Yes Yes 1,731<td>Yes Yes Yes 215 260 122.6% 388   Yes Yes Yes 1,245 558 46.7% 10,452   No No 5,014 435 9.0% 12,343   Yes No 778 524 67.9% 12,363   Yes No 1,163 518 48.5% 13,152   Yes Yes 2,580 1,084 45.6% 19,826   Yes Yes 2,422 1,833 77.762 52,271   No No 3,703 3,709 102.7% 52,271   No No 69 130 28.8% 10,142   No No 2,520 1,184 42.6% 3,504   No No Yes 4,351 627 14.2% 6,525   No Yes Yes 3,971 2,635 70.7% 3,898   No No No 1,531 102 6.4% 4,8</td><td>Yes Yes 1215 260 122.68 388 441   Yes Yes 1.245 558 46.76 10.452 7.852   No No No 5.014 435 9.074 13.034 14.774   Yes No 778 524 67.96 12.363 7.604   Yes No 1.163 518 48.554 13.152 57.33   Yes No 3.703 3.703 10.275 27.762 11.303   Yes No 3.0160 484.854 8.33 214 1.441   No No 3.0160 484.854 8.33 214 4.593   No No 1.30 26.86 3.04 3.593 3.64 3.593   Yes Yes 1.83 145 80.16 3.64 3.502 3.64   No No Yes 4.361 627 14.28 4.233 5.052   No No</td></td>	Yes Yes Yes 215   Yes Yes 1,245   No No 5,014   Yes Yes 8,384   Yes No 778   Yes No 1,163   Yes Yes 2,580   Yes Yes 2,422   Yes No 30   No No 4,361   Yes Yes Yes   Yes Yes 4,402   Yes Yes Yes   Yes Yes 1,715   Yes Yes Yes   Yes Yes 1,831   No No No   No No 1,715   Yes Yes Y	Yes Yes 215 260   Yes Yes 1,245 558   No No 5,014 4355   Yes Yes 8,384 7,522   Yes No 1,163 518   Yes Yes 2,580 1,084   Yes Yes Yes 2,580 1,084   Yes Yes No 3,703 3,709   No No No 30 160   No No S 167   No No S 167   No No S 167   No No 2,520 1,184   Yes Yes Yes 183   No No S 3,971   Yes Yes Yes 3,971   Yes Yes Yes 3,971   Yes Yes Yes 1,021   No No No 1,023	Yes Yes Yes 215 260 122.6%   Yes Yes 1,245 558 46.7%   No No No 778 524 67.9%   Yes No 1,163 5181 48.5%   Yes No 1,163 5181 48.5%   Yes Yes No 1,163 5181 48.5%   Yes No 3,703 3,709 102.7%   No No No 30 160 484.8%   No No No 856 130 28.8%   No No No 4,361 62.742 1,84 42.6%   Yes Yes Yes 130 28.8% 80.1% 80.1% 80.1% 80.1%   No No Yes A361 62.74 1.968 91.4%   Yes Yes Yes 1,715 170 12.7%   Yes Yes Yes 1,731 <td>Yes Yes Yes 215 260 122.6% 388   Yes Yes Yes 1,245 558 46.7% 10,452   No No 5,014 435 9.0% 12,343   Yes No 778 524 67.9% 12,363   Yes No 1,163 518 48.5% 13,152   Yes Yes 2,580 1,084 45.6% 19,826   Yes Yes 2,422 1,833 77.762 52,271   No No 3,703 3,709 102.7% 52,271   No No 69 130 28.8% 10,142   No No 2,520 1,184 42.6% 3,504   No No Yes 4,351 627 14.2% 6,525   No Yes Yes 3,971 2,635 70.7% 3,898   No No No 1,531 102 6.4% 4,8</td> <td>Yes Yes 1215 260 122.68 388 441   Yes Yes 1.245 558 46.76 10.452 7.852   No No No 5.014 435 9.074 13.034 14.774   Yes No 778 524 67.96 12.363 7.604   Yes No 1.163 518 48.554 13.152 57.33   Yes No 3.703 3.703 10.275 27.762 11.303   Yes No 3.0160 484.854 8.33 214 1.441   No No 3.0160 484.854 8.33 214 4.593   No No 1.30 26.86 3.04 3.593 3.64 3.593   Yes Yes 1.83 145 80.16 3.64 3.502 3.64   No No Yes 4.361 627 14.28 4.233 5.052   No No</td>	Yes Yes Yes 215 260 122.6% 388   Yes Yes Yes 1,245 558 46.7% 10,452   No No 5,014 435 9.0% 12,343   Yes No 778 524 67.9% 12,363   Yes No 1,163 518 48.5% 13,152   Yes Yes 2,580 1,084 45.6% 19,826   Yes Yes 2,422 1,833 77.762 52,271   No No 3,703 3,709 102.7% 52,271   No No 69 130 28.8% 10,142   No No 2,520 1,184 42.6% 3,504   No No Yes 4,351 627 14.2% 6,525   No Yes Yes 3,971 2,635 70.7% 3,898   No No No 1,531 102 6.4% 4,8	Yes Yes 1215 260 122.68 388 441   Yes Yes 1.245 558 46.76 10.452 7.852   No No No 5.014 435 9.074 13.034 14.774   Yes No 778 524 67.96 12.363 7.604   Yes No 1.163 518 48.554 13.152 57.33   Yes No 3.703 3.703 10.275 27.762 11.303   Yes No 3.0160 484.854 8.33 214 1.441   No No 3.0160 484.854 8.33 214 4.593   No No 1.30 26.86 3.04 3.593 3.64 3.593   Yes Yes 1.83 145 80.16 3.64 3.502 3.64   No No Yes 4.361 627 14.28 4.233 5.052   No No





#### Comparison to urban populations

Table 4 presents estimates from the NTR9 compared to single-race AI/AN population estimates for metropolitan and micropolitan statistical areas as defined by the U.S. Census Bureau and estimated from the 2009 American Community Survey (ACS). Metropolitan areas are defined as cities or urban areas with at least 50,000 residents, and micropolitan areas have at least 25,000 residents. Without getting specific about the boundaries of each metro/

micropolitan area, we added the number of NTR9 records with city of residence recorded as one of those cities listed in Table 4 under "Geography".

The ACS estimates show that approximately 55% of the AI/AN state population of Idaho resided in one of these metro/micropolitan areas, while only 29% of the NTR9 population was listed as residing in one of these cities. Similarly, the urban AI/AN population in Oregon was about 88% of the state's AI/AN population per ACS estimates, but only 44% of the NTR9 population; in Washington the proportions were 86% of the ACS population in urban areas vs. 38% of the NTR9 population. These results demonstrate that 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 large urban areas in the Northwest 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. The inclusion of patient records from Seattle Indian Health Board has increased the representativeness of the Seattle AI/ AN population above the IHS Area-wide Patient File alone, although our de-duplication methods make it impossible to quantify the extent of this difference.



Geography	population estimate (ACS)	Total AI/AN state population (ACS)	Percent of state population	NTR9 population – City of residence*	population represented	
IDAHO						
Boise City-Nampa, ID Metro Area	3,863			267	6.9%	
Coeur d'Alene, ID Metro Area	1,278			257	20.1%	
ldaho Falls, ID Metro Area	820			801	97.7%	
Lewiston, ID-WA Metro Area	2,813			1,220	43.4%	
Logan, UT-ID Metro Area	83			-	0.0%	
Pocatello, ID Metro Area	3,040			3,841	126.3%	
Tw in Falls, ID Micro Area	625			151	24.2%	
IDAHO METRO/MICRO AREA TOTAL	12,522	22,742	55.1%	6,537	28.7%	
Albany-Lebanon, OR Micro Area	1,716			938	54.7%	
Bend, OR Metro Area	1,642			606	36.9%	
Coos Bay, OR Micro Area	-			684	0.0%	
Corvallis, OR Metro Area	917			283	30.9%	
Eugene-Springfield, OK Metro Area	3,387			1,841	54.4%	
Grants Pass, OR Micro Area	444			147	33.1%	
Klamath Falls, OR Micro Area	3,832			2,440	03.8%	
Pendleten Hermisten OR Mare Area	1,177			207	17.0%	
Pendleton-Hermiston, OR Micro Area	2,311			2,080	90.0%	
Pontiand-Vancouver-Beaverton, OR-WA Metro Area	19,406			6,522	33.0%	
Roseburg, OR Micro Area	2,390			332	22.2%	
Salem, OK Metro Area	5,700			4,037	04.0%	
OREGON METRO/MICRO AREA TOTAL	42,936	48,611	88.3%	21,123	43.5%	
WASHINGTON						
Aberdeen, WA Micro Area	3,268			918	28.1%	
Bellingham, WA Metro Area	4,441			3,506	78.9%	
Bremerton-Silverdale, WA Metro Area	2,641			476	18.0%	
Centralia, WA Micro Area	494			221	44.7%	
Kennew ick-Pasco-Richland, WA Metro Area	1,959			789	40.3%	
Lewiston, ID-WA Metro Area	2,813			1,220	43.4%	
Longview, WA Metro Area	861			432	50.2%	
Moses Lake, WA Micro Area	1,395			213	15.3%	
Mount Vernon-Anacortes, WA Metro Area	1,512			723	47.8%	
Oak Harbor, WA Micro Area	672			108	16.1%	
Olympia, WA Metro Area	4,029			1,477	36.7%	
Port Angeles, WA Micro Area	3,065			1,371	44.7%	
Seattle-Tacoma-Bellevue, WA Metro Area	33,442			15,753	47.1%	
Spokane, WA Metro Area	4,599			3,057	66.5%	
Wenatchee-East Wenatchee, WA Metro Area	1,310			334	25.5%	
Yakima, WA Metro Area	9,451			3,186	33.7%	
WASHINGTON METRO/MICRO AREA TOTAL	75,952	87,973	86.3%	33,784	38.4%	
* Alive residents of ID, OR, or WA						





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#### Comparison to county populations

Table 5 compares NTR9 registrants by county of residence to NCHS bridged-race population estimates. As expected, the NTR9 more closely approximated AI/AN populations residing in CHSDA counties, since these are the service delivery areas of IHS and tribal clinics, are typically on or near Indian reservations, and tend to be populated more densely with AI/ANs than non-CHSDA areas. However, 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 (see Table 3 for cross-reference).

Table 5a. Idaho county population comparisons					
Shaded = CHSDA county					
County	County population estimate (NCHS)	NTR9 – County of residence	Percent of county pop represented		
Ada	3,911	250	6.4%		
Adams	60	11	18.3%		
Bannock	3,023	4,400	145.6%		
Bear Lake	40	35	87.5%		
Benewah	983	1,264	128.6%		
Bingham	3,243	4,871	150.2%		
Blaine	183	15	8.2%		
Boise	84	8	9.5%		
Bonner	512	125	24.4%		
Bonneville	901	839	93.1%		
Boundary	265	364	137.4%		
Butte	24	6	25.0%		
Camas	7	0	0.0%		
Canyon	2,392	115	4.8%		
Caribou	17	44	258.8%		
Cassia	301	174	57.8%		
Clark	10	5	50.0%		
Clearwater	248	369	148.8%		
Custer	36	41	113.9%		
Elmore	435	23	5.3%		
Franklin	83	58	69.9%		
Fremont	104	79	76.0%		

Table 5b. Idaho county population comparisons					
Shaded = CHSDA county					
County	County population estimate (NCHS)	NTR9 – County of residence	Percent of county pop represented		
Gem	176	20	11.4%		
Gooding	181	33	18.2%		
ldaho	608	293	48.2%		
Jefferson	208	229	110.1%		
Jerome	262	61	23.3%		
Kootenai	2,237	1,000	44.7%		
Latah	418	339	81.1%		
Lemhi	91	18	19.8%		
Lewis	201	772	384.1%		
Lincoln	76	16	21.1%		
Madison	211	77	36.5%		
Minidoka	304	184	60.5%		
Nez Perce	2,423	4,053	167.3%		
Oneida	17	15	88.2%		
Owyhee	500	6	1.2%		
Payette	275	20	7.3%		
Power	318	79	24.8%		
Shoshone	293	128	43.7%		
Teton	44	14	31.8%		
Twin Falls	752	221	29.4%		
Valley	73	25	34.2%		
Washington	102	6	5.9%		
Missing		291	1.4%		

Table 6a. Oregon county populationcomparisons						
	Shaded = CHSDA county					
County	County population estimate (NCHS)	NTR9 – County of residence	Percent of county pop represented			
Baker	227	56	24.7%			
Benton	969	442	45.6%			
Clackamas	4,574	2,005	43.8%			
Clatsop	546	152	27.8%			
Columbia	842	328	39.0%			
Coos	2,116	1,301	61.5%			
Crook	396	352	88.9%			
Curry	626	117	18.7%			
Deschutes	2,392	1,261	52.7%			
Douglas	2,182	1,504	68.9%			
Gilliam	20	13	65.0%			
Grant	147	66	44.9%			
Harney	388	441	113.7%			
Hood River	364	61	16.8%			
Jackson	2,884	491	17.0%			
Jefferson	3,677	5,640	153.4%			
Josephine	1,404	531	37.8%			
Klamath	3,504	3,895	111.2%			

# Table 6b. Oregon county populationcomparisons

Shaded = CHSDA county

County	County population estimate (NCHS)	NTR9 – County of residence	Percent of county pop represented
Lake	216	44	20.4%
Lane	5,344	2,320	43.4%
Lincoln	2,095	2,362	112.7%
Linn	1,959	1,544	78.8%
Malheur	448	49	10.9%
Marion	7,461	6,628	88.8%
Morrow	373	69	18.5%
Multnomah	10,594	5,013	47.3%
Polk	1,740	2,478	142.4%
Sherman	32	22	68.8%
Tillamook	421	260	61.8%
Umatilla	2,873	2,645	92.1%
Union	312	113	36.2%
Wallowa	61	29	47.5%
Wasco	1,136	399	35.1%
Washington	5,847	1,697	29.0%
Wheeler	21	15	71.4%
Yamhill	1,699	1,365	80.3%
Missing		485	1.0%

comparisons					
Shaded = CHSDA county					
County	County population estimate (NCHS)	NTR9 – County of residence	Percent of county pop represented		
Adams	589	32	5.4%		
Asotin	394	501	127.2%		
Benton	2,082	752	36.1%		
Chelan	1,085	339	31.2%		
Clallam	4,233	5,052	119.3%		
Clark	5,113	1,330	26.0%		
Columbia	50	8	16.0%		
Cowlitz	2,135	891	41.7%		
Douglas	789	262	33.2%		
Ferry	1,448	2,110	145.7%		
Franklin	886	206	23.3%		
Garfield	15	0	0.0%		
Grant	1,666	824	49.5%		
Grays Harbor	4,277	4,648	108.7%		
Island	896	199	22.2%		
Jefferson	843	214	25.4%		
King	22,421	11,961	53.3%		
Kitsap	4,827	2,281	47.3%		
Kittitas	556	245	44.1%		
Klickitat	833	613	73.6%		

Table 7a. Washington county population

# Table 7b. Washington county populationcomparisons

Shaded = CHSDA county

County	County population estimate (NCHS)	NTR9 – County of residence	Percent of county pop represented
Lewis	1,286	707	55.0%
Lincoln	281	127	45.2%
Mason	2,650	2,492	94.0%
Okanogan	4,973	7,089	142.5%
Pacific	690	805	116.7%
Pend Oreille	464	669	144.2%
Pierce	14,635	17,708	121.0%
San Juan	149	61	40.9%
Skagit	2,757	2,605	94.5%
Skamania	300	108	36.0%
Snohomish	12,178	8,551	70.2%
Spokane	8,835	3,710	42.0%
Stevens	2,792	4,023	144.1%
Thurston	4,889	2,497	51.1%
Wahkiakum	94	24	25.5%
Walla Walla	702	159	22.6%
Whatcom	6,525	5,796	88.8%
Whitman	472	230	48.7%
Yakima	13,554	17,091	126.1%
Missing		1,053	1.0%



### SUMMARY



This assessment of the NTR9 lends a degree of confidence in the completeness and representativeness of this demographic enumeration of the Northwest AI/AN population. 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).

The most notable divergence from Census-based population estimates was seen in age distributions. Younger age groups – most notably children ages 0 through 9 – were severely under-represented (ratio = 0.37), while the oldest age group, those over 80 years old, were over-represented

(ratio =1.5). 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. There is less concern about the over-represented older population, since the inclusion of deceased individuals will only result in those records not matching to databases of live registrants, and in fact, may be advantageous in linkages to death records, cancer registries, and other surveillance systems in which some registrants may have died. Most age groups in NTR9 (ages 20-79) were proportionally similar to NCHS population distributions, leading us to believe that most of our record linkage work does not disproportionately correct only certain age subgroups of AI/AN disease registrants.

Geographic distributions of the NTR9 population varied widely across the three states, and depending on which variables were used to assess them. 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%). As expected, the NTR9 better represented AI/ANs in CHSDA areas than non-CHSDA counties, rural areas compared to urban areas, and tribal and IHS service populations where there is an RPMSreporting clinic. These findings are consistent with the sources of our data.

Although there are many limitations to the NTR9 data and comparisons made in this report, in general we feel that the NTR9 is a valid representation of the Northwest AI/AN population, appropriate for identifying AI/ANs across a range of disease surveillance systems in Idaho, Oregon, and Washington. The results of this assessment will allow us to focus future efforts on incorporating supplemental data sources from certain under-represented tribes/service units and urban areas, which will in turn allow us to more completely correct racial misclassification and more effectively report health status data on these AI/AN subpopulations. This assessment also helps us better understand the strengths and limitations of linkage results with different surveillance data sources.



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