**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

Key findings

* 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.

**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 |
| \*\* Alive residents of ID, OR, or WA |