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Racial Misclassification and Disparities in Neonatal Abstinence Syndrome among American Indians and Alaska Natives

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Abstract

Objectives: Maternal substance misuse can result in neonatal abstinence syndrome (NAS), a drug withdrawal process in newborns exposed in utero to drugs. This study aimed to examine the effect of racial misclassification of American Indians and Alaska Natives (AI/AN) on rates of NAS in two hospital discharge datasets in the Pacific Northwest.

Methods: We conducted probabilistic record linkages between the Northwest Tribal Registry and Oregon and Washington hospital discharge datasets to correct racial misclassification of AI/AN people. We assessed outcomes using International Classification of Disease, Ninth Revision/Tenth Revision, Clinical Modification (ICD-9-CM or ICD-10-CM) diagnosis codes.

Results: Linkage increased ascertainment of NAS cases among AI/AN by 8.8% in Oregon, and by 18.1% in Washington. AI/AN newborns were 1.5 and 3.9 times more likely to be diagnosed with NAS than NHW newborns in Oregon and Washington, respectively. The results showed that newborns residing in rural Washington were 1.4 times more likely to be diagnosed with NAS than those living in urban areas.

Conclusions: Correct racial classification is an important factor in improving data quality for AI/AN populations and establishing accurate surveillance to help address the disproportionate burden of neonatal abstinence syndrome among AI/AN. The results highlight the need for programing efforts tailored by insurance status and rurality for pregnant women using substances.

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Declarations
Availability of data and material: Please send any request to the author.
Code availability: The author can provide the analysis codes via request.
Compliance with Ethical Standards
Ethics approval: All project protocols were reviewed and approved by the Institutional Review Board (IRB) from the Portland Area Indian Health Service and state IRBs when applicable.

Keywords

American Indians and Alaska Natives; racial misclassification; neonatal abstinence syndrome; racial disparities

BACKGROUND

Use and misuse of substances during pregnancy has become a global public health concern. The United States is facing considerable increases in maternal opioid use and the negative effects on infants [1, 2]. Maternal substance misuse can result in neonatal abstinence syndrome (NAS), a drug withdrawal process in newborns exposed in utero to drugs. NAS is often caused when a pregnant woman misuses pharmaceutical opioids, either prescribed or not, or other drugs during pregnancy. Opioids may be prescribed as painkillers following injury or surgery. Other drugs taken during pregnancy that might lead to NAS include antidepressants, benzodiazepines commonly prescribed for anxiety, or other illicit drugs such as heroin. Across the United States, every 25 minutes a baby is born suffering from NAS, resulting in a nearly 500% increase nationally since 2000 [2]. These drugs pass through the placenta and can cause serious health problems for newborns, including sudden infant death, breathing and feeding problems, or seizures [3]. It may also lead to long-term adverse consequences such as impairments in cognitive and behavioral outcomes [4].

American Indians and Alaska Natives (AI/AN) have been disproportionately affected by the opioid epidemic. Yet, the health status of AI/AN has not been measured accurately due to racial misclassification in health-related datasets [5–8]. AI/AN are misclassified in surveillance and administrative datasets (e.g., death certificates, cancer registry, etc.) more frequently than other races or ethnicities, with misclassification ranging between 30% and 70% [9–13]. Racial misclassification continues to result in inaccurate morbidity and mortality rates for AI/AN populations [14–1], making it difficult to establish baselines, track changes, and accurately measure health disparities for AI/AN. The data on how AI/AN newborns are affected by NAS is scarce. Thus, the current study aims to examine the impacts of racial misclassification in measuring AI/AN hospital births, and assess the magnitude of neonatal abstinence syndrome among hospital deliveries in Oregon and Washington.

METHODS

All project protocols were reviewed and approved by the Institutional Review Board (IRB) from the Portland Area Indian Health Service and state IRBs when applicable.

Data Sources

This cross-sectional study utilized two states' hospital inpatient discharge datasets. Oregon inpatient discharge data from years 2010 to 2017 (N = 2,957,469 records) were provided by the Office for Oregon Health Policy and Research at the Oregon Health Authority. The Oregon data exclude Veterans Administration hospitals, specialty or rehabilitative care hospitals, long-term care facilities, and psychiatric hospitals. Washington data for years 2011 to 2016 (N = 3,854,110 records) were provided by the Comprehensive Hospital Abstract Reporting System (CHARS) at the Washington State Department of Health. The data were submitted by hospital medical records departments to the State Hospital Commission from all non-federal and non-state-run hospitals in Washington. To be considered as an inpatient discharge, the patient must have stayed a minimum of one day in the hospital. Hospital stay information include diagnoses, procedures, costs and payers. All inpatient hospital visits for AI/AN residing in Oregon and Washington are provided through community hospitals since there is no Indian Health Service (IHS) or tribally-run hospital in the Northwest. Thus, most hospitalizations for AI/AN patients in the region should be recorded in the Oregon and Washington hospital discharge systems (albeit AI/AN may be misclassified in administrative datasets).

Probabilistic Record Linkage

In this study, Oregon and Washington hospital discharge data were corrected for AI/AN misclassification through probabilistic record linkage with the Northwest Tribal Registry (NTR). The NTR is a database that includes records of AI/AN patients who have received services at IHS, Tribal, or Urban Indian Health Programs in Idaho, Oregon, or Washington State. The database does not contain tribal enrollment data, and includes individuals affiliated with Tribes outside the Northwest region. The Northwest Tribal Registry version 14 file has a total of 214,529 records.

Probabilistic record linkage has been used as a non-invasive way to improve the accuracy of race classification in administrative data for AI/AN populations [10]. Previous studies have documented the process and results of using record linkage to improve race data quality for AI/AN in inpatient hospital discharge datasets as well as in examining disparities in life expectancy using linkage-corrected life tables [12,17].

For this study, we used the probabilistic record linkage software packages LinkPlus version 2.0 (developed by the Centers for Disease Control and Prevention) and Match*Pro (developed by Information Management Services, Inc). Both software packages were developed based on Fellegi and Sunter models [18]. Prior to linkage, we performed data cleaning and standardization for the NTR following best practices guidelines [19]. We used the software to link the NTR to the state hospital discharge data using blocking and matching variables including SSN (last four digits for CHARS), date of birth (year, month, day), name (first, last, and middle using NYSIIS), sex, and ZIP code. In order to reduce possible research bias due to data linkage errors, we used blocking techniques to reduce comparison space and had multiple blocking passes to minimize the potential effect of errors in a set of blocking variables. All matched pairs were reviewed by two trained project staff members to identify “true” or “false” matches. Differences between reviewers were resolved by assigning the more conservative determination on match status (i.e., that the pair did not match). All personal identifiers were removed after linkage. For the final AI/AN count, we included in the analyses all matched cases (those originally coded as AI/AN plus the misclassified cases identified by linkage with the NTR records), as well as non-matched cases that were originally coded as AI/AN in the hospital discharge datasets.

Measures

Consistent with previous methodology, we used the International Classification of Disease, Ninth Revision/Tenth Revision, Clinical Modification ICD-9-CM and ICD-10-CM codes to identify in-hospital births among all hospital records (V30.X-V39.X ending in 00 or 01; Z38.0 – Z38.8 indicating single or multiple live born infants). Neonatal abstinence syndrome diagnosis was identified using the ICD-9-CM or ICD-10-CM diagnosis code. The following ICD-9-CM code was included: 779.5 (drug withdrawal syndrome in a newborn). The corresponding ICD-10-CM code, P96, was used for records that were discharged after October 1st, 2015. Currently, there is no single ICD-9/10-CM code that captures NAS with sufficient sensitivity and specificity. Therefore, in conducting any examination of NAS using ICD-9/10-CM, the codes applied are used as a proxy for NAS-related diagnoses. In hospital discharge data, there is a principal diagnosis as well as a number of secondary diagnoses for each record. The *principal diagnosis* is that condition considered to be chiefly responsible for the patient's admission to the hospital. *Secondary diagnoses* are concomitant conditions that coexisted at the time of admission or developed during the hospital stay. For this analysis, we included records with NAS diagnosis codes in either the principal or any secondary diagnoses fields. The rate of discharges for NAS was described as per 1,000 hospital births.

Primary payers were grouped into the following categories: public sources (Medicaid and Medicare) and other government sponsored programs (e.g., Department of Defense, Department of Veterans Affairs, Indian Health Service), private insurance, self-pay, and other types. Other patient characteristics include patient residence categorized into urban vs. rural.

We followed the methodology used in the 2013 National Center for Health Statistics (NCHS) Urban-Rural Classification Scheme for Counties to classify urban or rural counties in Washington and Oregon. All counties and county-equivalent entities were assigned to one of the six levels (four metropolitan and two nonmetropolitan). *Purchased/Referred Care Delivery Areas* (PRCDA) consist of counties that contain federally recognized tribal lands or are adjacent to tribal lands, and any counties which have a common boundary with a reservation. We used state and county FIPS codes to determine whether the patient residence location was in a PRCDA county and whether the facility discharged from was located in a PRCDA county.

Misclassification. We generated a dichotomous variable indicating whether a record was misclassified or not. Those that matched with the NTR and were not documented as AI/AN in the original dataset were categorized as misclassified.

Statistical Analyses

First, we calculated descriptive statistics and frequencies to describe the sample characteristics. Chi-square tests and t-tests were performed to assess whether AI/AN and Non-Hispanic White (NHW) newborns vary in their demographic or hospitalization characteristics (e.g., sex, resident location, primary payer, length of hospital stay). We then examined whether the rates of NAS per 1,000 hospital deliveries differed between AI/AN and NHW newborns. Next, we evaluated the effect of misclassification by comparing pre- and post-linkage NAS rates. Additionally, we analyzed whether the difference between pre- and post-linkage NAS rates were statistically significant in AI/AN and NHW, respectively. Rate ratios (RR) between pre- and post-linkage NAS rates were calculated for both groups. Further, we investigated the characteristics of the misclassified records (e.g., geographic location, primary payer, etc.). We conducted logistic regression modelling to analyze possible variables associated with misclassification on hospital birth records. A set of predictor variables were included, such as year of discharge, rurality of patient resident location, and length of hospital stay. Similar regression modelling was conducted to investigate possible variables associated with a NAS diagnosis among newborns. All data management and statistical analyses were conducted using SAS statistical software version 9.4 (SAS Institute Inc., Cary, NC, USA).

RESULTS

Linkage Results of Hospital Discharge Data

The AI/AN records in the analytic dataset included all AI/AN documented in the original inpatient hospital discharge data as well as those records matched with the Northwest Tribal Registry (NTR). A total of 132,492 AI/AN were included in the statistical analysis. Of these records, 26.0% were misclassified as a race other than AI/AN in the original hospital discharge datasets. Figure 1 describes the results of the record linkage and identification of AI/AN records included in this analysis. Among the records that matched with the NTR, about half (49.8%) were misclassified (55.2% and 47.5% in Oregon and Washington, respectively). Among post-linkage AI/AN records, 26.0% were misclassified in the original datasets. Data linkages resulted in a 35.1% increased ascertainment of AI/AN (post-linkage percent increase in the proportion of hospital discharge records classified as AI/AN).

Characteristics of Hospital Births

The dataset contained 471,252 hospital deliveries in Washington between years 2011 – 2016 (including 7,817 AI/AN deliveries and 192,058 NHW deliveries), and 330,923 deliveries in Oregon reported from 2010 to 2017 (including 4,345 AI/AN deliveries and 171,170 NHW deliveries). Table 1 shows the characteristics of hospital births in Oregon and Washington by race. A significantly higher percentage of AI/AN newborns had public insurance and resided in rural areas than NHW newborns. The percentage of AI/AN newborns with a NAS diagnosis was significantly higher than NHW in both Oregon and Washington (Oregon 0.9% vs 0.6%, $p = 0.005$; Washington 4.4% vs 1.1%, $p < 0.0001$).

Linkage and NAS Disparities

Table 2 shows the impacts of the probabilistic linkage. Linkage increased ascertainment of NAS cases among AI/AN by 8.8% in Oregon, and by 18.1% in Washington (calculated as the difference between post-linkage and pre-linkage NAS case count divided by pre-linkage NAS case count). In both states, the rate of NAS per 1,000 AI/AN hospital births decreased after linkage, yet AI/AN newborns continued to have a higher chance of being diagnosed with NAS than NHW newborns (AI/AN vs NHW Rate Ratio = 1.5 and 3.9 in Oregon and Washington, respectively).

Misclassification among AI/AN Newborns

Table 3 describes characteristics of the newborn that were misclassified. AI/AN newborns residing in rural areas were more likely to be misclassified in hospital discharge data than those living in urban areas. There were a total of 4,345 and 7,817 AI/AN hospital births in Oregon and Washington respectively from 2010 to 2017. Among all AI/AN newborns in Oregon, a higher proportion of misclassified newborns resided in rural areas compared to those correctly classified (57.6% vs. 43.8%, $p < 0.0001$), while no significant difference was found in newborns in Washington. Further, misclassified AI/AN newborns had a shorter mean length of hospital stay than those that were not misclassified (2.8 vs. 3.2 days, respectively, $p <$ 0001). This held true in both Oregon and Washington. Compared with correctly classified AI/AN newborn, in Oregon a lower proportion of misclassifed AI/AN newborns had public insurance (60.1% vs. 73.5%, $p < 0.0001$). In Washington, there was little difference in the proportion of newborns that had public insurance between misclassified and correctly classified (54.0% and 55.3%, respectively), but a higher proportion of misclassified Washington AI/AN newborns had private insurance (29.3% vs. 21.9%). Similar to Oregon, misclassified newborns in Washington had a shorter length of hospital stay than non-misclassified newborns (3.2 vs. 4.1 days, $p = 0.0003$).

Table 4 shows the association between misclassification and patient characteristics. The individual-level predictors included primary payer, whether the patient resided in a rural area, and length of hospital stay. The results showed that Oregon AI/AN newborns residing in rural areas were two times more likely to be misclassified (Odds Ratio = 2.1, 95% CI = 1.76, 2.47). In Washington, none of the individual-level predictors were significantly associated with misclassification.

Factors Associated with NAS Diagnosis

In Oregon, the odds of NAS diagnosis among newborns was higher among those with public insurance (OR = 6.5, 95% CI = 5.6, 7.6), while those residing in rural areas had a lower chance of being diagnosed with NAS (OR = 0.5, 95% CI = 0.4, 0.6). Contrary to Oregon, newborns in Washington were more likely to have a NAS diagnosis if they lived in a rural area (OR = 1.4, 95% CI = 1.3, 1.6); while those with public insurance in Washington had lower odds of having NAS (OR = 0.2, $p < 0.001$). After controlling for insurance status and patient resident rurality, race was not significantly associated with a NAS diagnosis among newborns in either Oregon or Washington.

DISCUSSION

Implications for Research

The findings underscore not just state-level variability in the Northwest, but also highlight the racial disparities between AI/AN and NHW. The results show a higher rate of NAS diagnosed among hospital births in Washington compared to Oregon, similar to a previous report that conducted a multistate analysis and showed a higher rate of opioid use disorders (OUD) among hospital births in Washington than in Oregon (10.8 vs. 8.4 per 1,000 births in 2014) [20]. Assessments of the contribution that differing state policies might have on state-to-state variability in opioid use disorders and NAS diagnosis are scarce. Further research is needed to evaluate the impacts of state policies on the prevalence of NAS.

The current study investigates the scope of neonatal abstinence syndrome in Northwest AI/AN communities. Further research is needed in order to gain a better understanding of the factors that contribute to higher burden of the disease among AI/AN and how those factors interact with one another, including behavioral and environmental risk factors. A recent study showed that systematic barriers remain for women with OUD to access medications, and in particular, among pregnant women with OUD [21]. Stigma related to pregnant women with substance use disorders continues to pose considerable challenges in linking women to needed treatment. Given the uniqueness of AI/AN communities, it is critical to establish trust and work with these communities to improve access to health care services for women with substance use disorders especially ensuring equitable access to mental health services that are culturally-centered, address the legacy tied to historical trauma, and included trauma-informed care [22–27].

Implication for Practice

The findings underscore the importance of correcting racial misclassification in obtaining accurate data for AI/AN communities. Conducting record linkages is one tool to ensure that AI/AN populations are counted accurately in health data. Accurate data are critical for establishing baselines for monitoring disease burden and disparities. Collection of race or ethnicity data has improved over time in Oregon and Washington [28, 29]. We saw in the datasets that the percentages of missing or unknown race information have declined over the years, yet there is still a significant proportion (about 25%) of misclassified AI/AN in each state hospital discharge dataset. This study demonstrates that the inaccuracy of collected race/ethnicity continues to pose challenges when using hospital discharge data to assess the health status of AI/AN communities in these states. There is a need for concerted efforts to improve the completeness and accuracy of race/ethnicity data across health and public health data systems. A potentially promising practice may be the implementation of Oregon's HB-2134, which establishes uniform standards and requirements for collection of data on race, ethnicity, preferred languages, and disabilities in many health data systems.

The results further illustrate need for intervention to be geographically and culturally tailored. A previous study suggested that the incidence of NAS is rising in rural areas [30], similar to the observation for Washington. This result is in parallel with rising rural rates of opioid misuse related conditions and drug overdose deaths [31]. Despite rural-urban disparities in NAS, AI/AN newborns were still disproportionately affected. There is an urgent need for culturally sensitive and competent programs to support AI/AN women who use substances during pregnancy, particularly tailored for those with public insurance in Oregon, and those residing in rural areas in Washington.

Limitations

There are several limitations to this study. First, the study results cannot be generalized to all AI/AN populations. Second, our linkage with hospital discharge data may not have identified all misclassified AI/AN records in the Oregon and Washington datasets. A previous evaluation of the representativeness of the NTR shows that the dataset includes an estimated 75 to 80% of the total AI/AN population living in the Northwest region. The IHS patient registration data (which makes up the majority of records in the Northwest Tribal Registry) includes patients receiving health services directly at IHS, tribal, and urban Indian facilities. Some AI/AN individuals may not be included in IHS patient data due to eligibility requirements or lack of knowledge, among other reasons. Further, AI/AN people with private insurance who do not receive care through the IHS/Tribal/Urban health care system are not represented in the NTR. Therefore, while we were able to address misclassification to some extent in this analysis, some AI/AN birth and NAS records may have been missed, leading to underestimation of NAS counts and rates. Nonetheless, the linkages revealed substantial misclassification and underreporting of AI/AN race in hospital discharge datasets. Lastly, our reliance on ICD codes that indicated confirmed diagnosis of drug withdrawal symptoms among newborns may have excluded records of newborns that did not have a confirmed diagnosis but had in-utero drug exposure.

Conclusion

Findings from this study highlight the racial and regional differences in neonatal abstinence syndrome. Correct racial classification is an important factor in improving data quality for AI/AN populations and establishing accurate surveillance to help address the disproportionate burden of neonatal abstinence syndrome among AI/AN. The results highlight the needs for programing efforts tailored by insurance status and rurality for pregnant women using substances.

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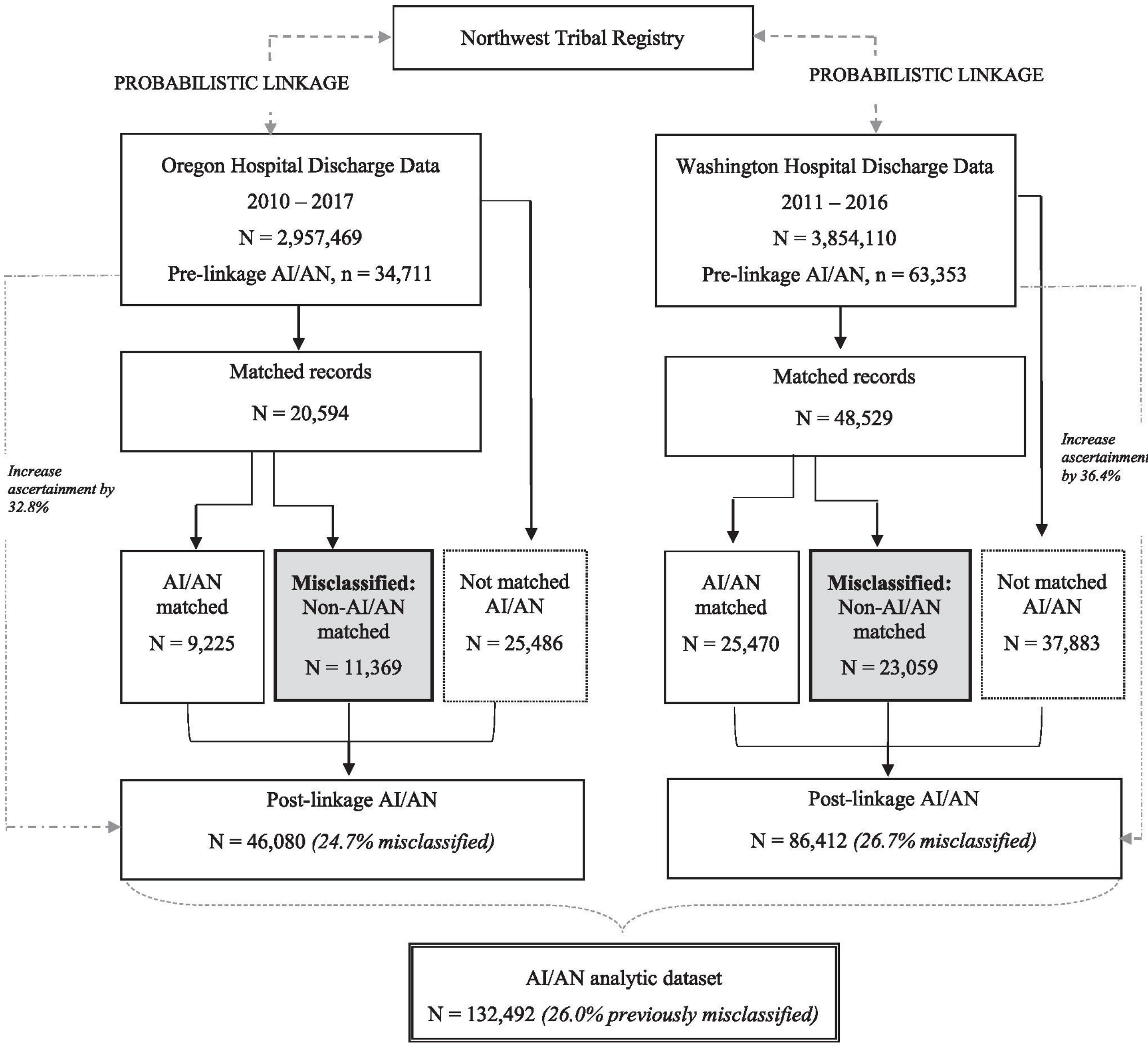

Figure 1. Flowchart of the record linkage from inpatient hospital discharge data and derivation of American Indian and Alaska Native (AI/AN) hospitalizations in Oregon and Washington between 2010 and 2017

Note. AI/AN not matched with Northwest Tribal Registry were retained in the post-linkage AI/AN records.

Table 1

Characteristics of AI/AN and Non-Hispanic White Hospital Births in Oregon and Washington State, 2010 – 2017

Year	**Oregon 2010 – 2017**			**Washington 2011 – 2016**		
	AI/AN N (%)	**NHW N (%)**	**p**	**AI/AN N (%)**	**NHW N (%)**	**p**
Total hospital deliveries	N = 4,345	N = 171,170		N = 7,817	N = 192,058	
Sex			0.99			0.82
Female	2,108 (48.5)	82,982 (48.5)		3,808 (48.7)	92,897 (48.4)	
Male	2,235 (51.4)	88,111 (51.5)		4,009 (51.3)	99,160 (51.6)	
Insurance [§]			< 0.0001			< 0.0001
Public	3,099 (71.3)	7,1226 (41.6)		4,294 (54.9)	57,155 (29.8)	
Private	1,025 (23.6)	92,394 (54.0)		1,888 (24.2)	103,397 (53.8)	
Self-pay	126 (2.9)	5,484 (3.2)		164 (2.1)	3,450 (1.8)	
Other	95 (2.2)	2,066 (1.2)		1,471 (18.8)	28,056 (14.6)	
Length of hospital stay (days)			0.39			< 0.0001
Mean (SD)	3.2 (7.1)	3.1 (7.1)		3.8 (9.5)	3.0 (7.7)	
Patient residence location			< 0.0001			< 0.0001
Urban	2,344 (53.9)	141,315 (82.6)		6,233 (79.7)	173,116 (90.1)	
Rural	2,001 (46.1)	29,855 (17.4)		1,584 (20.3)	18,941 (9.9)	
Neonatal abstinence syndrome			0.005			< 0.0001
Count, n (%)	41 (0.9)	1,039 (0.6)		346 (4.4)	2,183 (1.1)	

Note. AI/AN = American Indians and Alaska Natives post-linkage. NHW = Non-Hispanic White. SD = standard deviation.

[§] In Oregon and Washington, public payer includes Medicaid, Medicare, and other government sponsored patients; private health insurance includes health maintenance organization (HMO), health service contractor, as well as other private and commercial health insurance.

Table 2

Pre- and Post- Linkage Neonatal Abstinence Syndrome Rates among AI/AN and Non-Hispanic White Hospital Births in Oregon and Washington

Year	**Oregon 2010 – 2017**		**Washington 2011 – 2016**	
	AI/AN	NHW	AI/AN	NHW
Hospital deliveries				
Pre-Linkage	3,632	171,535	5,465	192,677
Post-Linkage	4,345	171,170	7,817	192,058
Neonatal abstinence syndrome, N (rate * *)*				
Pre-Linkage	37 (10.2)	1,041 (6.1)	293 (53.6)	2,197(11.4)
Post-Linkage	41 (9.4)	1039 (6.1)	346 (44.3)	2,183 (11.4)
AI/AN: NHW Rate Ratio				
Pre-Linkage	1.7		4	
Post-Linkage	1.5		3.9	
Pre- and Post-Linkage AI/AN Rate Ratio	0.9		0.8	

Note. AI/AN = American Indians and Alaska Natives; NHW = Non-Hispanic White

* Neonatal abstinence syndrome rate was calculated per 1,000 hospital deliveries; AI/AN linkage rate ratio was calculated using pre-linkage AI/AN count divided by post-linkage AI/AN count.

Table 3

Characteristics of Misclassified American Indian and Alaska Native Newborns in Inpatient Hospital Discharge Data, 2010 – 2017

Year	**Oregon 2010 – 2017**	**Washington 2011 – 2016**
Total AI/AN hospital births, N	4,345	7,817
Misclassified records, n (%)	713 (16.5)	2,352 (30.1)
Sex		
Male	361 (50.6)	1,218 (51.8)
Female	352 (49.4)	1,134 (48.2)
Primary payer, %		
Public	429 (60.2) *	1,270 (54.0) *
Private	255 (35.8)	690 (29.3)
Self-pay	14 (1.9)	43 (1.8)
Other	15 (2.1)	349 (14.8)
Length of hospital stay		
Days, mean (SD)	2.8 (6.0) *	3.2 (8.6) *
Original race coding §		
White	393 (55.1)	619 (26.7)
Other	222 (31.1)	309 (13.1)
Missing/Unknown	198 (27.8)	1,424 (60.5)
Patient residence location		
Rural	411 (57.6) *	431 (18.3)
Urban	302 (42.4)	1,921 (81.7)
Reside in PRCDA County		
Yes	705 (98.9)	2342 (99.6) *
Discharged from facility in PRCDA County Yes	620 (87.0)	2340 (99.5) *

Note.

* $p < 0.05$ indicates difference found between misclassified records and those not misclassified. SD = standard deviation.

§ In Oregon, Original race was coded in one variable, while there were multiple race variables in Washington data. Thus, only those coded as white and not American Indians and Alaska Natives were included in the original race coding as "White". PRCDA = Purchased/Referred Care Delivery area.

Table 4

Multiple Logistic Regression Models on Misclassification of AI/AN among Hospital Births in Washington and Oregon, 2010 – 2017

	Oregon		Washington	
	Odds Ratio	**95% CI**	**Odds Ratio**	**95% CI**
Year	0.80	0.77, 0.83	0.98	0.95, 1.01
Public Insurance	0.47	0.39, 0.56	0.99	0.89, 1.10
Rural (Ref = Urban)[§]	2.09	1.76, 2.47	0.83	0.73, 0.94
Length of stay	0.99	0.98, 1.01	0.99	0.98, 1.00

Note.

[§]Indicating patient residence. CI = Confidence interval.