

American Indian and Alaska Native Mental Health Research



Volume 33, Issue 1, 2026

**Centers for American Indian &
Alaska Native Health**

colorado school of public health

American Indian and Alaska Native Mental Health Research

Volume 33, Number 1, 2026

Editor-in-Chief
Spero M. Manson, PhD

Journal Manager
Sara Mumby, MA, MPH

The Role of Racial Disaggregation in Understanding AI/AN Adolescent Suicidal Behavior: Assessment of the Youth Risk Behavior Surveillance System 1

Parker Smith, DO (Choctaw Nation), Kayleigh Noblin, BA (Cherokee Nation), Amy Hendrix-Dicken, PhD (Cherokee Nation), Michael Dunlap, DO, and Micah Hartwell, PhD

Systematic Review and Meta-Analysis of Anxiety and Depression Among American Indian and Alaska Native Adolescents in the United States 14

Phyllis Chan, PhD, Abdelrahman M Makram, MBBCh, Valentín Quiroz de la Sierra (Yo'eme), PhD, Samantha Alvarez Madrazo, PhD, Nosha Assareh, PhD, Nick Jayanth, MSc, and Mary Cwik, PhD

Understanding the Drivers of Perceived PrEP Stigma among Indigenous People in the United States 41

Monica M. Desjardins, MPH (Diné), Jessica Leston, MPH (Tsimshian), Erica N. Browne, MS, Sarah M. Hatcher, PhD, Brigg Reilley, MPH, Ashley Hoover, MPH, Andrew Freeman, BA, Matthew Bensen, MA, Bob Henne, BS, and Sarah T. Roberts, PhD

Engaging Urban American Indian/Alaska Native Emerging Adults in a Nationwide Substance Use Intervention Randomized Controlled Trial: A Story of Recruitment during the COVID-19 Pandemic 65

Daniel L. Dickerson, DO, MPH (Inupiaq), Mel Borstad, MA, Ninna Gudgell, BA, Keisha McDonald, BS, Jennifer Parker, BA, Paige Smith, CPS, CADC-1 (Paiute, Modoc-Enrolled Klamath Tribes), Pierrce Holmes, MA, Michael J. Woodward, Carrie L. Johnson, PhD (Wahpeton Dakota), and Elizabeth J. D'Amico, PhD

ISSN 1533-7731

©2026 Centers for American Indian and Alaska Native Health
Aurora, Colorado
All Rights Reserved

The Role of Racial Disaggregation in Understanding AI/AN Adolescent Suicidal Behavior: Assessment of the Youth Risk Behavior Surveillance System

Parker Smith, DO (Choctaw Nation), KayLeigh Noblin, BA (Cherokee Nation), Amy Hendrix-Dicken, PhD (Cherokee Nation), Michael Dunlap, DO, and Micah Hartwell, PhD

***Abstract:** This study compared rates of suicidal ideation and suicide attempts among adolescents categorized as American Indian/Alaska Native (AI/AN) using the computed raceeth variable in the Youth Risk Behavior Surveillance System (YRBSS) to those identified through self-reported ethnoracial identity. We conducted a cross-sectional analysis of the 2021 YRBSS, examining rates of suicidal ideation and attempts using both the raceeth variable and self-reported ethnoracial combinations. Population-weighted percentages were calculated using survey design and sampling weights. Adolescents categorized as AI/AN (non-Hispanic) using the raceeth variable had population-weighted suicidal ideation and attempt rates of 27.3% and 21.85%, respectively. However, those self-reporting as AI/AN with multiple ethnoracial identities had significantly higher rates. Suicidal ideation was highest among AI/AN + White (Hispanic) at 42.3%, AI/AN + Black (non-Hispanic) at 33.3%, and AI/AN + Black + White (non-Hispanic) at 41.05%. Suicide attempts were highest for AI/AN + Black + White (non-Hispanic) at 43.6% and AI/AN + White (Hispanic) at 32.43%. The raceeth variable may exclude key AI/AN subgroups at elevated risk. Addressing disparities among multiracial AI/AN adolescents requires healthcare awareness and inclusive public health research methods.*

INTRODUCTION

Suicide is one of the leading causes of death in the United States, accounting for 48,183 deaths in 2021 alone (CDC, 2023b). Children and young adults are particularly impacted by suicide with it being the second leading cause of death for children 10-14 and the third leading cause of death for individuals 15-24 (CDC, 2023b). Suicide disproportionately impacts individuals across sociodemographic factors, including ethnoracial groups where non-Hispanic American Indians and Alaska Natives (AI/AN) experience 28.1 deaths from suicide per 100,000 individuals (Ivey-Stephenson et al., 2017; CDC, 2023b). Additionally, within this group, another national survey—the National Violent Death Reporting System—showed a 20% increase in suicide from 2015-2020, compared to a less than 1% increase among the overall U.S. population (Stone et al., 2022). In an examination of suicidal ideation and suicide attempts among adolescent students aged 12-19 in the Minnesota Student Survey, individuals reported as AI/AN demonstrated elevated rates compared to other ethnic groups (Wiglesworth et al., 2022).

While these datasets show the rate of suicide is highest among non-Hispanic AI/AN peoples, rates of suicide and suicidal ideation may vary from what is included within these surveys as a result of data genocide (Friedman et al., 2023). Data genocide can be defined as the erasure or aggregation of data that can lead to deleterious health outcomes in Indigenous communities (Friedman et al., 2023). Many large-scale datasets, including the Bureau of Labor Statistics and the Centers for Disease Control and Prevention (CDC), only recognize AI/ANs when those individuals identify as single-race, non-Hispanic AI/AN—a category that only represents 23% of all AI/ANs. Data genocide and racial misclassification can mean AI/AN individuals often do not receive adequate resources, including healthcare (Maxim et al., 2023). This ultimately results in the reduction of vital resources, thus further perpetuating health disparities (Haozous et al., 2014). Recent research has shown that computed race/ethnicity variables in national datasets overwhelmingly place AI/AN individuals in other categories (Gatewood et al., 2024).

Given that racial classification aggregation may affect reported rates of health behaviors, the primary aim of this study was to compare the rates of suicidal ideation and suicide attempts among AI/AN adolescents using the computed *raceeth* variable in the Youth Risk Behavior

Surveillance System (YRBSS) to the self-reported ethnoracial identity among all adolescents identifying as AI/AN alone, AI/AN with other races, and AI/AN with Hispanic ethnicity.

METHODS

We performed a cross-sectional analysis of the 2021 YRBSS, a national survey conducted by the CDC, which includes state, territorial, tribal, and local-school-based surveys of 9th- through 12th-grade students from 45 states across the country (CDC, 2023c). YRBSS is used to determine the prevalence of youth health behaviors among various student demographics (CDC, 2023c).

Race & Ethnicity

Adolescents can self-report their race; however, YRBSS combines the participants' race and ethnicity to formulate the *raceeth* variable. This variable is separated into three classifications based on adolescent responses: a singular race designation if only one race is selected, a multiple race designation if more than one race is selected, and the Hispanic ethnicity designation, irrespective of the selection of another race.

Suicidal Behaviors

To evaluate suicidal ideation, we utilized the following question from YRBSS: “*In the last 12 months, did you ever seriously consider attempting suicide?*” Participants were given a ‘yes’ or ‘no’ response option. Additionally, to assess suicide attempts, we used the following question: “*In the last 12 months, how many times did you actually attempt suicide?*” Responses ranged from 0 times to 6 or more times, which was recorded as a binary variable to assess if the participant reported making a suicide attempt or not.

Statistical Analyses

Employing the survey design and sampling weights provided by YRBSS, we reported the sample size and the population-weighted percentages of self-reported AI/AN alone with and without Hispanic ethnicity, and in combination with other races, and within the *raceeth* variable—which reflects the previous work by Gatewood et al. (Gatewood et al., 2024). From these groups, we calculated the prevalence of suicidal ideation and suicide attempts by each subgroup. Statistical significance was determined through non-overlapping 95% confidence intervals; however, only ethnoracial groups whose denominator was ≥ 30 were analyzed per the 2021 methodological

guidelines of YRBSS (CDC, 2023a; Mpofu et al., 2023). Analyses were conducted in Stata v19 (StataCorp, LLC., College Station, TX), which allows for modeling data with complex survey design and sampling weights.

Ethical Statement

This study was determined to be non-human subjects research by the Oklahoma State University Institutional Review Board. This study adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.

RESULTS

The sample size of individuals self-identifying as AI/AN was 816, with 3.9% and 8.3% of missing data among the assessed suicide ideation and attempts questions, respectively, which were omitted from analysis. Our analyses revealed that among all AI/AN individuals, 27.74% (94 out of 340) of those with Hispanic ethnicity and 29.60% (130 out of 444) without Hispanic ethnicity reported suicidal ideation, compared to YRBSS's previously imputed *raceeth* variable with 27.3% (37 out of 143) reporting suicidal ideation, corresponding to only those who self-reported as single-race, non-Hispanic AI/AN (Table 1). Within the self-reported race/ethnicity data, we found higher rates of suicidal ideation within several groups, including AI/AN + White (Hispanic) at 42.31%, AI/AN + Black or African American (non-Hispanic) at 33.33%, and AI/AN + Black or African American + White (non-Hispanic) at 41.05% (Table 1).

When evaluating rates of suicide attempts, we found that 24.06% (75 out of 331) of AI/AN individuals with Hispanic ethnicity and 24.08% (107 out of 417) of those without Hispanic ethnicity reported attempting suicide (Figure 1). This is compared to the *raceeth* variable's single-race, non-Hispanic AI/AN participant rate of 21.85% (32 out of 129; Table 1). Within the self-reported race/ethnicity data, the groups with the highest rates of attempting suicide were AI/AN + Black or African American + White (non-Hispanic) at 43.6% and AI/AN + White (Hispanic) at 32.43% (Table 1); however, the confidence intervals overlapped within all groups with samples greater than 30 (Figure 1).

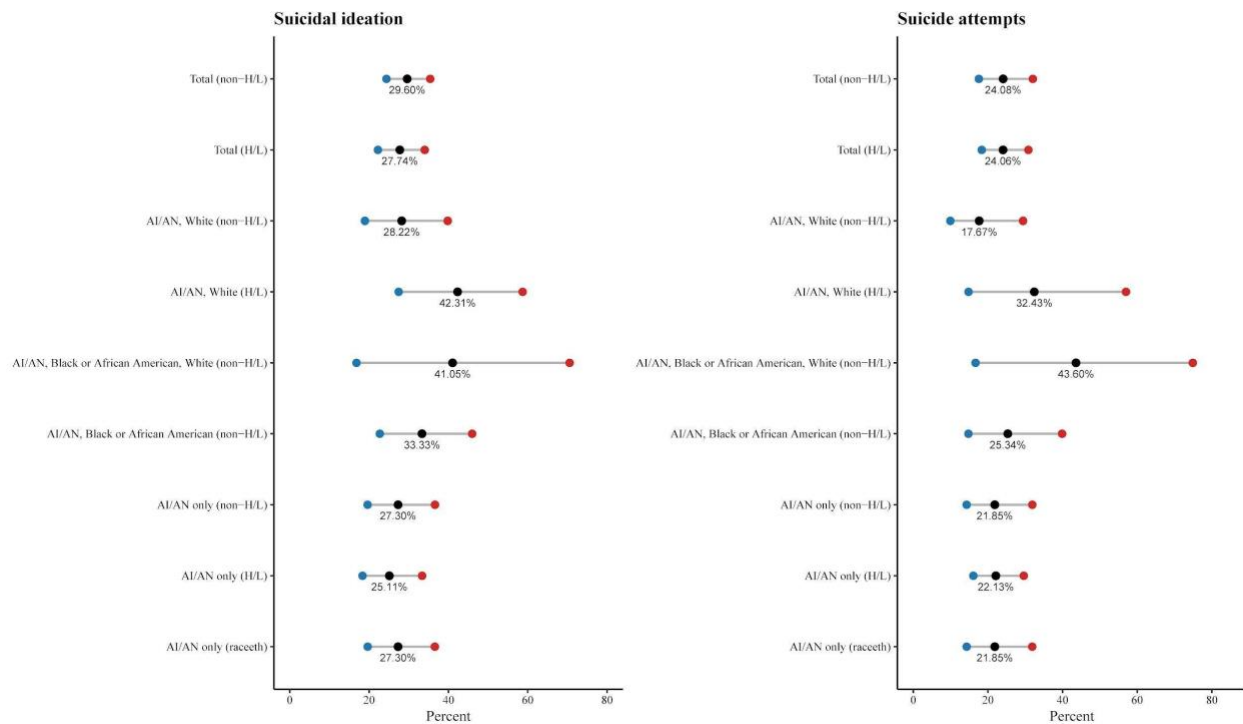
RACIAL DISAGGREGATION AND AI/AN YOUTH SUICIDE 5

Table 1.
Percentage of adolescents who reported ever seriously considering attempting suicide (suicidal ideation) and reported suicide attempts in the past 12 months by self-reported and imputed ethnoracial groupings in YRBSS

	Suicidal ideation		Suicide attempts	
	Hispanic or Latino	Non-Hispanic or Latino	Hispanic or Latino	Non-Hispanic or Latino
	No. (%)	No. (%)	No. (%)	No. (%)
<i>Raceeth variable from YRBSS</i>				
*AI/AN only	-	37 of 143 (27.30)	-	32 of 129 (21.85)
<i>Self-selected race from YRBSS</i>				
AI/AN only	61 of 242 (25.11)	37 of 143 (27.30)	49 of 237 (22.13)	32 of 129 (21.85)
AI/AN, White	15 of 39 (42.31)	52 of 172 (28.22)	11 of 38 (32.43)	40 of 161 (17.67)
AI/AN, NH/PI	1 of 4	0 of 0	1 of 4	0 of 0
AI/AN, NH/PI, White	0 of 4	1 of 2	0 of 4	1 of 2
AI/AN, Black or African American	8 of 22 (26.79)	20 of 64 (33.33)	8 of 21	12 of 61 (25.34)
AI/AN, Black or African American, White	0 of 5	11 of 30 (41.05)	0 of 4	10 of 31 (43.60)
AI/AN, Black or African American, NH/PI	0 of 1	1 of 1	0 of 1	1 of 1
AI/AN, Black or African American, NH/PI, White	1 of 1	0 of 1	1 of 1	1 of 1
AI/AN, Asian	1 of 6	0 of 4	1 of 6	1 of 4
AI/AN, Asian, White	0 of 0	2 of 9	0 of 0	2 of 9
AI/AN, Asian, NH/PI	0 of 1	2 of 2	0 of 1	1 of 2
AI/AN, Asian, NH/PI, White	0 of 1	1 of 2	0 of 1	1 of 2
AI/AN, Asian, Black or African American	2 of 2	1 of 1	0 of 2	0 of 1
AI/AN, Asian, Black or African American, White	1 of 1	0 of 2	1 of 1	0 of 2
AI/AN, Asian, Black or African American, NH/PI	1 of 1	0 of 0	1 of 1	0 of 0
AI/AN, Asian, Black or African American, NH/PI, White	3 of 10	2 of 10	2 of 9	4 of 10
All Race combinations including other races not listed	0 of 0	0 of 1	0 of 0	1 of 1
Total	94 of 340 (27.74)	130 of 444 (29.60)	75 of 331 (24.06)	107 of 417 (24.08)

*Only group in YRBSS aggregate race variable (*raceeth*) indicating AI/AN. The *raceeth* variable is calculated by YRBSS and provided for researchers to use. Statistics reported here are the number of respondents within the sample group and weighted percentages. Percentages are not displayed for groups with denominators < 30 as indicated by YRBSS methodology.

Figure 1. Prevalence of adolescents who reported ever seriously considering attempting suicide (suicidal ideation) and reported suicide attempts in the past 12 months by self-reported and imputed ethnorracial groupings in YRBSS among those with > 30 participants



DISCUSSION

Our study showed that significant segments of the AI/AN community are excluded from the reported data within YRBSS, which is consistent with previous findings (Gatewood et al., 2024). Notably, AI/AN adolescents with ethnorracial combinations of White and Black/African American exhibited the highest rates of both suicidal ideation and suicide attempts, with both groups having point estimates 12-21% higher than AI/AN alone (non-Hispanic) from the *raceeth* variable.

Our findings for individuals classified as AI/AN alone reflect national estimates of suicidal ideation and suicide attempts reported within previous work. This includes a 2018 study by Subica and Wu, which found the rates of suicidal ideation in this population to be 25.43%, compared to our 27.3%, and the suicide attempt rate to be 16.77%, compared to our 21.85%, which is in line with increasing rates over the last 10 years (Stone et al., 2022; Subica & Wu, 2018). The Minnesota Student survey from 2022 reflects some of the elevated rates of suicidal ideation and suicide

attempts within several of the multiracial AI/AN groups. In this study, adolescents identifying as AI/AN and Black/African American, as well as AI/AN and White, exhibited elevated rates of suicidal ideation compared to the monoracial AI/AN group (Wiglesworth et al., 2022).

Additionally, the elevated rates of suicidal ideation and attempts in multiracial AI/ANs may relate to research showing elevated rates of depression in multiracial groups from lacking a sense of belonging (Sanchez, 2010). According to a systematic review from 2016-2022, most multiracial individuals reported worse mental health outcomes than their monoracial peers (Oh et al., 2024), with multiracial adolescents displaying less internal pride and cultural connectivity, which could lead to a diminished sense of belonging (Charmaraman & Grossman, 2010).

Implications & Recommendations

The findings of our study have several notable implications both for researchers, clinicians, and policy makers. First, the findings underscore the need for disaggregated race and ethnicity data in large data sets (Gatewood et al., 2024)—specifically by including the self-reported identity variables. While YRBSS provides this disaggregated data, which is a notable strength of the data, other large data sets do not. Further, a shift in research methodology needs to occur to account for the complexity of identity, when possible, particularly for AI/AN individuals given the history of federal assimilation policies—a sentiment shared by Friedman et al. in their investigation in data genocide among AI/AN populations regarding deaths of despair (Friedman et al., 2023). A recent report using 2020 Decennial Census data indicated that 61% of AI/AN individuals were classified as multiracial (Maxim et al., 2023). As such, it is imperative that researchers and agencies creating large data sets begin to account for the complexity of identity in their respective work. This shift in practice will allow for more precise reporting of group strengths and areas for intervention, likely enhancing future public health initiatives focused on suicide prevention.

In 2021, an American Academy of Pediatrics policy statement titled “Caring for American Indian and Alaska Native Children and Adolescents” touched specifically on suicide and mental health for AI/AN populations and considerations for treatment (Bell et al., 2021). Current recommendations include community-driven interventions that are both strength-based and culturally centered (Bell et al., 2021). Further, providers must be aware of the possible impact of historical trauma on the mental health of Indigenous populations (Bell et al., 2021; Mohatt et al., 2014). Possible interventions include treatment modalities such as “Honoring Children, Mending the Circle” (HC-MC), a trauma-focused cognitive-based therapy (TF-CBT) for AI/AN children

(Bigfoot, 2022; BigFoot & Schmidt, 2009, 2010). This particular treatment method was created by merging AI/AN cultural components with the traditional TF-CBT framework (BigFoot & Schmidt, 2009, 2010). It is important to note that frameworks such as HC-MC are recommended for individuals with a strong AI/AN cultural affiliation (BigFoot & Schmidt, 2010). As such, providers should assess an individual's cultural affiliation instead of making assumptions about affiliation based solely on self-reported race and ethnicity (BigFoot & Schmidt, 2010). It is also critical that providers demonstrate the cultural competence needed to refer adolescents and their families to AI/AN providers specializing in culturally centered health care delivery when it is in the best interests of the child's health (Kodjo, 2009).

For both primary care and mental health providers, especially those within the osteopathic profession, assessing and triaging suicide risk is a vital part of clinical practice and a necessary part of holistic care. Identifying children at risk for suicide is critical on an individual, community, and population level. Valid suicide-risk stratification requires clinicians to be aware of the level of risk associated with certain patient demographics such as age, race, ethnicity, socioeconomic factors, and past psychiatric history. By extension, clinicians are dependent on the data that qualifies the level of risk. Professionals should reflect and take an active role to ensure their individual practices, organizations, and healthcare systems are properly identifying high risk populations.

Limitations and Future Research

While YRBSS lacks nationwide representation, with only 45 of the 50 states participating, it is one of the largest youth data sets available for assessing youth health and risk behaviors (CDC, 2023d). Furthermore, the data collection process for YRBSS relies on self-reporting, which enables adolescents to provide their own responses. This introduces a potential self-report bias, which may result in underreporting of suicidal ideation and suicide attempts. Adolescents could be minimizing their experiences in order to avoid perceived stigma and unwanted help (Deming et al., 2021). Future studies may extend this line of research to investigate differences among other ethnoracial groups, as well as explore other differences among self-reported identity. This is a particularly important topic for future research, including with Native Hawaiians and Pacific Islanders (NHPI), a group that also includes a high rate of multiracial individuals (Maxim et al., 2023). Further, evidence remains that some state and federal agencies are still labeling NHPI

individuals under the label “Asian American or Pacific Islander,” despite guidance in 1997 that created the NHPI race/ethnicity category (Quint et al., 2023).

CONCLUSION

As the *raceeth* variable within YRBSS captures only single-race, non-Hispanic AI/AN youth, our study found it excluded nearly 61% of youth identifying as AI/AN within the dataset representing a substantial proportion of AI/AN youth being systematically excluded from analyses using this variable. Our findings demonstrate that this aggregation obscures meaningful variation in suicidal ideation and attempts and contributes to ongoing data erasure, limiting the visibility of disparities within AI/AN communities. These findings underscore the need for surveillance systems to adopt inclusive racial classification approaches that allow for multiracial identification and disaggregated reporting to ensure more accurate representation of youth to inform targeted, culturally responsive suicide prevention efforts.

ACKNOWLEDGEMENTS

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

FUNDING INFORMATION

This work was supported by NICHD U54HD113173.

CONFLICT OF INTEREST

Dr. Hartwell has received research funding from the National Institute of Child Health and Human Development (U54HD113173), Human Resources Services Administration (U4AMC44250-01-02 and R41MC45951), and from the National Institute of Justice (2020-R2-CX-0014). Dr. Hendrix-Dicken also received funding from the National Institute of Child Health and Human Development (U54HD113173).

AUTHOR INFORMATION

Parker Smith, DO (Choctaw Nation), is an anesthesiology resident at Houston Methodist Hospital in Houston, TX. He conducted this research through the Office of Medical Student Research, Oklahoma State University College of Osteopathic Medicine at Cherokee Nation in Tahlequah, OK.

KayLeigh Noblin, BA (Cherokee Nation), is a DO candidate at the Office of Medical Student Research, Oklahoma State University College of Osteopathic Medicine at Cherokee Nation in Tahlequah, OK.

Amy Hendrix-Dicken, PhD (Cherokee Nation), is a Senior Research Associate in the Department of Pediatrics at the University of Oklahoma School of Community Medicine in Tulsa, OK.

Michael Dunlap, DO, is a Child and Adolescent Psychiatrist in the Department of Pediatrics and the Department of Psychiatry at the University of Oklahoma School of Community Medicine in Tulsa, OK.

Micah Hartwell, PhD, is a Clinical Assistant Professor in the Department of Psychiatry and Behavioral Sciences at Oklahoma State University Center for Health Sciences in Tulsa, OK, and the Director of the Office of Medical Student Research at Oklahoma State University College of Osteopathic Medicine at Cherokee Nation in Tahlequah, OK.

REFERENCES

- Bell, S., Deen, J. F., Fuentes, M., Moore, K., & Committee on Native American Child Health. (2021). Caring for American Indian and Alaska Native children and adolescents. *Pediatrics*, 147(4). <https://doi.org/10.1542/peds.2021-050498>
- Bigfoot, D. S. (2022, June 22). Supporting tribal youth at risk for suicide: Honoring children, mending the circle. YouTube. <https://www.youtube.com/watch?v=yNAQWTHg3oU>
- BigFoot, D. S., & Schmidt, S. R. (2009). Science-to-practice: Adapting an evidence-based child trauma treatment for American Indian and Alaska native populations. *International Journal of Child Health and Human Development*, 2(1), 33–44. <https://psycnet.apa.org/fulltext/2009-21187-004.pdf>

- BigFoot, D. S., & Schmidt, S. R. (2010). Honoring children, mending the circle: Cultural adaptation of trauma-focused cognitive-behavioral therapy for American Indian and Alaska Native children. *Journal of Clinical Psychology, 66*(8), 847–856. <https://doi.org/10.1002/jclp.20707>
- Charmaraman, L., & Grossman, J. M. (2010). Importance of race and ethnicity: an exploration of Asian, Black, Latino, and multiracial adolescent identity. *Cultural Diversity & Ethnic Minority Psychology, 16*(2), 144–151. <https://doi.org/10.1037/a0018668>
- Centers for Disease Control and Prevention. (2023a). 2021 YRBS Data User's Guide. https://www.cdc.gov/healthyyouth/data/yrbs/pdf/2021/2021_YRBS_Data_Users_Guide_508.pdf
- Centers for Disease Control and Prevention [CDC]. (2023b). Suicide Data and Statistics. <https://www.cdc.gov/suicide/suicide-data-statistics.html>
- Centers for Disease Control and Prevention [CDC]. (2023c). Youth Risk Behavior Surveillance System (YRBSS) Participation. <https://www.cdc.gov/healthyyouth/data/yrbs/participation.html>
- Deming, C. A., Harris, J. A., Castro-Ramirez, F., Glenn, J. J., Cha, C. B., Millner, A. J., & Nock, M. K. (2021). Inconsistencies in self-reports of suicidal ideation and attempts across assessment methods. *Psychological Assessment, 33*(3), 218–229. <https://doi.org/10.1037/pas0000976>
- Friedman, J., Hansen, H., & Gone, J. P. (2023). Deaths of despair and Indigenous data genocide. *The Lancet, 401*(10379), 874–876. [https://doi.org/10.1016/S0140-6736\(22\)02404-7](https://doi.org/10.1016/S0140-6736(22)02404-7)
- Gatewood, A., Hendrix-Dicken, A. D., & Hartwell, M. (2024). Comparing self-reported and aggregated racial classification for American Indian/Alaska Native youths in YRBSS: 2021. *American Journal of Public Health, e1–e4*. <https://doi.org/10.2105/AJPH.2023.307561>
- Haozous, E. A., Strickland, C. J., Palacios, J. F., & Solomon, T. G. A. (2014). Blood politics, ethnic identity, and racial misclassification among American Indians and Alaska Natives. *Journal of Environmental and Public Health, 2014*, 321604. <https://doi.org/10.1155/2014/321604>

- Ivey-Stephenson, A. Z., Crosby, A. E., Jack, S. P. D., Haileyesus, T., & Kresnow-Sedacca, M.-J. (2017). Suicide trends among and within urbanization levels by sex, race/ethnicity, age group, and mechanism of death - United States, 2001-2015. *Morbidity and Mortality Weekly Report Surveillance Summaries*, 66(18), 1–16. <https://doi.org/10.15585/mmwr.ss6618a1>
- Kodjo, C. (2009). Cultural competence in clinician communication. *Pediatrics in Review*, 30(2), 57–63; quiz 64. <https://doi.org/10.1542/pir.30-2-57>
- Maxim, R., Sanchez, G. R., & Huysen, K. R. (2023). Improving Federal data collection on Native Americans. <https://policycommons.net/artifacts/4139751/why-the-federal-government-needs-to-change-how-it-collects-data-on-native-americans/4948014/>
- Mohatt, N. V., Thompson, A. B., Thai, N. D., & Tebes, J. K. (2014). Historical trauma as public narrative: A conceptual review of how history impacts present-day health. *Social Science & Medicine*, 106, 128–136. <https://doi.org/10.1016/j.socscimed.2014.01.043>
- Mpofu, J. J., Underwood, J. M., Thornton, J. E., Brener, N. D., Rico, A., Kilmer, G., Harris, W. A., Leon-Nguyen, M., Chyen, D., Lim, C., Mbaka, C. K., Smith-Grant, J., Whittle, L., Jones, S. E., Krause, K. H., Li, J., Shanklin, S. L., McKinnon, I., Arrey, L., ... Roberts, A. M. (2023). Overview and methods for the Youth Risk Behavior Surveillance System - United States, 2021. *MMWR Supplements*, 72(1), 1–12. <https://doi.org/10.15585/mmwr.su7201a1>
- Oh, H., Winn, J. G., Li Verdugo, J., Bañada, R., Zachry, C. E., Chan, G., Okine, L., Park, J., Formigoni, M., & Leane, E. (2024). Mental health outcomes of multiracial individuals: A systematic review between the years 2016 and 2022. *Journal of Affective Disorders*, 347, 375–386. <https://doi.org/10.1016/j.jad.2023.11.040>
- Quint, J., Matagi, C., & Kaholokula, J. K. (2023). The Hawai'i NHPI data disaggregation imperative: Preventing data genocide through statewide race and ethnicity standards. *Hawai'i Journal of Health & Social Welfare*, 82(10 Suppl 1), 67–72. <https://doi.org/10.1093/CID/CIAA815>
- Sanchez, D. T. (2010). How do forced-choice dilemmas affect multiracial people? The role of identity autonomy and public regard in depressive symptoms. *Journal of Applied Social Psychology*, 40(7), 1657–1677. <https://doi.org/10.1111/j.1559-1816.2010.00634.x>

- Stone, D., Trinh, E., Zhou, H., Welder, L., End Of Horn, P., Fowler, K., & Ivey-Stephenson, A. (2022). Suicides among American Indian or Alaska Native persons - National Violent Death Reporting System, United States, 2015-2020. *Morbidity and Mortality Weekly Report*, 71(37), 1161–1168. <https://doi.org/10.15585/mmwr.mm7137a1>
- Subica, A. M., & Wu, L.-T. (2018). Substance use and suicide in Pacific Islander, American Indian, and multiracial youth. *American Journal of Preventive Medicine*, 54(6), 795–805. <https://doi.org/10.1016/j.amepre.2018.02.003>
- Wiglesworth, A., Clement, D. N., Wingate, L. R., & Klimes-Dougan, B. (2022). Understanding suicide risk for youth who are both Black and Native American: The role of intersectionality and multiple marginalization. *Suicide & Life-Threatening Behavior*, 52(4), 668–682. <https://doi.org/10.1111/sltb.12851>

Systematic Review and Meta-Analysis of Anxiety and Depression Among American Indian and Alaska Native Adolescents in the United States

Phyllis Chan, PhD, Abdelrahman M Makram, MBBCh, Valentín Quiroz de la Sierra (Yo'eme), PhD, Samantha Alvarez Madrazo, PhD, Nosha Assareh, PhD, Nick Jayanth, MSc, and Mary Cwik, PhD

Abstract: *American Indian and Alaska Native (AI/AN) adolescents experience considerable mental health disparities, yet research on the prevalence of anxiety and depression remains limited. The objectives of this study were to assess available depression and anxiety data among AI/AN adolescents in the literature and to estimate depression prevalence and mean scores. A systematic review of the Medline, Embase, and PsycINFO databases identified publications reporting on anxiety or depression in AI/AN adolescents aged 10-19. Gray literature was searched in ProQuest Dissertation and Theses to minimize publication bias. Meta-analyses using random-effects models in R estimated the aggregate prevalence and mean scores of depression. Covariates included mean age, percent of male participants, geographical region, and setting. The systematic literature review extracted 82 relevant studies, with 77 citations reported depression data, 15 citations reported anxiety data, and 4 citations reported depression and anxiety prevalence data together but did not discriminate between the two conditions. Aggregate depression prevalence measured by the Center for Epidemiological Studies Depression (CES-D) scale was 34.6% (95% CI: 11.5-68.4%) across three studies (N=664), while the Children's Depression Index (CDI) indicated a prevalence of 14.5% (95% CI: 2.5-52.9%) in two studies (N=365). The aggregate CDI mean score was 9.81 (95% CI: 9.50-10.13) out of 54. No covariates significantly influenced depression outcomes ($p > 0.05$). Generalized Anxiety Disorder 7-item*

(GAD-7) scale was the most frequently reported measurement of anxiety, in three studies. Due to limited data, meta-analyses for anxiety were not conducted. The results of this systematic review highlight the scarcity of data on depression and anxiety in AI/AN adolescents. This underscores the urgent need for culturally appropriate, evidence-based mental health research and services for AI/AN adolescents.

INTRODUCTION

In the United States, major depression and anxiety are among the most prevalent mental health disorders, with an estimated prevalence of 8.3% and 19.1%, respectively (NIMH, 2023; NIMH, n.d.). The American Indian and Alaska Native (AI/AN) population had the highest depression rate (11.2%) among all racial and ethnic groups, except for people who were associated with two or more races (NIMH, 2023; NIMH, n.d.). Research shows that mental health disorders like depression and anxiety can manifest at any age, including adolescence. Anxiety disorders in adults often begin as high levels of anxiety in childhood (NIMH, 2024). These mental health disorders can have direct impacts on quality of life, underscoring the urgent need to understand and address these mental health challenges among AI/AN youths.

Anxiety and depression have strong associations with substance abuse and are risk factors for suicide (Cheref et al., 2019). Specifically, adolescents aged 12 to 17 years with depressive symptoms are at higher risk of poor academic achievement (Tyser et al., 2014) and substance abuse and misuse, including cigarette smoking (Moon et al., 2020). AI/AN adolescents have the highest rates of cigarette smoking (Yu & Whitbeck, 2016) and suicide ideation (Baiden et al., 2020) among all racial and ethnic groups in the United States and are the only ethnic minority group with higher rates than Whites. Suicide is the second leading cause of death among AI/AN adolescents (Asher BlackDeer & Patterson Silver Wolf, 2020), which marks anxiety and depression as major public health concerns in the United States, especially for the AI/AN population.

Despite elevated mental health risks, the AI/AN population faces various barriers when seeking mental healthcare, including stigma associated with mental health problems, shortage of Indigenous service providers, and chronic underfunding of the Indian Health Service (IHS) (Gone & Trimble, 2012; Goodkind et al., 2010; Grandbois, 2005). Adding to the severity of the mental healthcare landscape, AI/AN adolescents remain underrepresented in mental health research (Alcantara & Gone, 2007; Storck et al., 2009). Considerable disparities and knowledge gaps in the mental health of AI/AN adolescents are formally recognized by major professional medical organizations (American Academy of Pediatrics, 2023; American Medical Association, 2021; American Psychological Association Services Inc, 2023; National Alliance on Mental Health, n.d.). Preventing, diagnosing, and treating mental illness during adolescence may help improve the

disproportionally high rates of substance abuse and suicide among the AI/AN population (Whitbeck, 2011).

Although 9.7 million people in the United States self-identify as AI/AN, either alone or in combination with other races (Sanchez-Rivera et al., 2023), there are a relatively small number of publications on anxiety and depression in the AI/AN population. As a population, AI/AN communities are culturally and geographically diverse, with members belonging to over 500 federally recognized tribes in 48 contiguous states and Alaska (United States Census Bureau, 2025). However, the vast majority of the AI/AN population (87%) do not live on one of the 324 federally recognized American Indian reservations or off-reservation trust land. Instead, most of the AI/AN population (70%) live in urban instead of rural areas of the United States (U.S. Department of Health and Human Services, Office of Minority Health [USDHHS OMH], 2025). An existing study suggested regional differences as a factor for variations in the prevalence of depression within the AI/AN population, as the tribes in the Northern Plains were found to have slightly higher percentage of adolescents experiencing depression compared to adolescent tribal members from the Southwest region, and this regional difference may be related to the more individualist culture among tribes in the Northern Plains compared to those in the Southwest (Novins et al., 1999).

The scarcity of available mental health data related to AI/AN adolescents partly stems from the data limitations within prominent health databases, such as those maintained by the National Institute of Mental Health (NIMH). The NIMH summary of major depression in adolescents excluded AI/ANs due to the small sample size in this racial group (NIMH, 2023; NIMH, n.d.). IHS does collect extensive individual-level mental health data of the AI/AN population (IHS, 2018); however, as healthcare eligibility through the IHS typically requires tribal membership (IHS, n.d.-a) and approximately only half of AI/AN tribal members receive health services through IHS (USDHHS OMH, 2025), the IHS electronic health records database might not be representative of the AI/AN population in the United States, and the database is also not focused on the adolescent population. Furthermore, the use of electronic health records to estimate the prevalence of health conditions could be associated with biases such as underrepresentation (Chen et al., 2022).

Given the limitations on available data, systematic reviews and meta-analyses, as the highest level in the hierarchy of evidence (Cochrane UK, 2023), offer a critical method for synthesizing existing research and identifying prevalence patterns in AI/AN adolescents across

various geographic and cultural contexts. While past reviews have examined the potential risk and protective factors for mental health among AI/AN individuals, families, and communities (Ka'apu, 2019), they lack a focus on examining the specific prevalence estimates for depression and anxiety. For depression, the authors recognized that, in general, older age and lower educational level were risk factors, and high level of social support and self-efficacy were protective factors, but significant variability in the risk factors was found between gender and geographic regions. However, the authors did not identify the endpoints used to quantify anxiety and depression in the six citations included in the systematic review.

A criterion on the measurement tools utilized to assess anxiety or depression is important when performing systematic reviews or meta-analyses of mental health problems in AI/AN populations. Because AI/AN communities may articulate and express distress in culturally specific ways, instruments developed primarily with non-Indigenous samples could misclassify, as well as over- or under-detect symptoms (Ka'apu, 2019). Moreover, stereotypes about AI/AN peoples and culturally divergent understandings of mental illnesses can amplify public and self-stigma, shaping help-seeking, disclosure, and engagement with care, which in turn may decrease identification in research and clinical screening (Gone & Trimble, 2012; Goodkind et al., 2010; Grandbois, 2005). Given the limited mental health data, evidence synthesis can provide an important interim approach. To our knowledge, no prior systematic review or meta-analysis has reported on the prevalence of anxiety or depression among AI/AN adolescents.

To address these gaps, we conducted a systematic review and meta-analysis to estimate the prevalence and mean scores of depression and anxiety among AI/AN adolescents. The study's objectives include: 1) evaluate the extent of available data; and 2) estimate prevalence and mean scores to investigate any potential variations between geographic regions.

METHODS

The protocol for the systematic review and meta-analysis was developed based on the Joanna Briggs Institute Manual for Evidence Synthesis (Joanna Briggs Institute, n.d.) and the Preferred Reporting Items for Systematic reviews and Meta-Analyses Protocols (PRISMA-P) checklist (Moher et al, 2015; Shamseer et al., 2015).

Search Strategy

A systematic search was conducted on three electronic databases: Medline, Embase, and PsycINFO. Medline and Embase are two large databases with concentrations in the biomedical field, while PsycINFO is a database specializing in the field of psychology, which encompasses the study of anxiety and depressive disorders. The search included citations from Ovid Epub Ahead of Print, In-Process, In-Data-Review, and other Non-Indexed Citations. To minimize publication bias, gray literature was searched in ProQuest Dissertation and Theses. The primary key terms, shown in Supplemental Table 1 in the [Supplemental File](#), were developed based on the Population, Intervention, Comparison, and Outcome (PICO) framework (Higgins & Green, 2009). An experienced medical information specialist at the Imperial College London (ICL) library reviewed the search strategy to ensure relevance and feasibility.

Inclusion and Exclusion Criteria

A set of inclusion and exclusion criteria (Table 1) was determined prior to identifying relevant studies. According to the World Health Organization (World Health Organization, n.d.), adolescents are defined as 10 to 19 years of age. This definition was selected to maintain consistency with global adolescent mental health research. To extract the maximum number of citations, there were no limitations on the study sample size or the publication year.

Study Selection

Search was conducted via the ICL library online access, with the search results downloaded and duplicates removed using EndNote 21 (Clarivate Analytics, Philadelphia). Only English language citations were considered. After the removal of duplicates, titles and abstracts from the citations were screened for topical relevance. For citations lacking clear abstracts, full texts were reviewed during the study selection process. Two independent reviewers assessed each study's eligibility through title and abstract screening and full-text review. Discrepancies between reviewers were resolved through discussion until a consensus was achieved.

Quality Assessment

The methodological quality and risk of bias of the included studies were evaluated using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for cross-sectional studies (University of Bern Institute of Social and Preventive Medicine, n.d.).

Table 1.
Inclusion and exclusion criteria of studies to be assessed for the systematic review

	Studies were included if:	Studies were excluded if:
Population	<ul style="list-style-type: none"> • The study population consisted of subjects between 10 and 19 years, or a separate breakdown of prevalence by age group, or at least included an age range covering most of the 10 to 19 years, was reported • The study focused on a special population (e.g., adolescents with psychological disorders or exposed to trauma), as long as a control group was also included in the study, but studies of pregnancy in adolescents or COVID-19 pandemic were not considered as special conditions as they are not automatically correlated with a mental or behavioral issue 	<ul style="list-style-type: none"> • The study population was not located in the continental United States (i.e., data from Native Hawaiians/Pacific Islanders and indigenous people in other parts of North/South America were excluded)
Outcome	<ul style="list-style-type: none"> • The study examined the effectiveness of anxiety or depression treatments and the validation of assessment tools, as long as a control group or baseline measurement was also included in the study • The prevalence of anxiety or depression was determined using standardized validated instruments, self-reported questionnaires, or clinically structured interviews • The prevalence was reported either as percentages, or at least enough information was provided so that the point prevalence, one-year prevalence, or lifetime prevalence could be calculated 	<ul style="list-style-type: none"> • The study did not report the prevalence or mean scores of either anxiety or depression independently from other mental health disorders
Other considerations	<ul style="list-style-type: none"> • Any study design, including cohort, case-control, and cross-sectional studies 	<ul style="list-style-type: none"> • No primary data analysis was published (e.g., review, editorial, systematic review, meta-analysis types of manuscript) • The study results were not reported in English

Data Extraction and Derivation

The two reviewers independently undertook data extraction following a standardized format based on the PRISMA checklists. Extracted data included: study identification (title, publication year, author), study setting and study design (geographical region, geographical setting, number of participants), subject characteristics (age, gender, special population, disorder),

and outcome (measurement tool, reported prevalence/mean score of anxiety and/or depression). For results reported in graphical format, data were extracted using WebPlotDigitizer (v4.5) (Automeris LLC, n.d.).

In addition to data extraction, the database-building process included data derivations to support the meta-analysis. If prevalence was not reported, the value was calculated using the sample size as the denominator, and the reported number of those with depression or anxiety as the numerator. Additionally, if a study lacked both standard error (SE) value and 95% confidence interval (95% CI), SE was calculated using this equation: $SE = \sqrt{p*(1-p)/n}$, where \sqrt{p} is the square root of the proportion of the cases reported, and n is the denominator of the prevalence estimate (Ferrari et al., 2013).

Meta-analysis

Meta-analyses were conducted to estimate the prevalence of anxiety or depression among AI/AN adolescents, based on the two most commonly utilized measurement tools each for anxiety and depression in the systematic review, when there was sufficient data extracted from the literature.

Both fixed-effect and random-effects models were first examined to assess the impact of data heterogeneity by comparing results from the two approaches (Borenstein et al., 2010). The random-effects model was then selected to estimate the 95% CI of the summary effect and to test for covariate effect (Han & Eskin, 2011), using subgroup analysis for categorical covariates or regression analysis for continuous covariates. For prevalence endpoints, meta-analyses for estimating aggregate proportion values were performed using the generalized linear mixed model (GLMM) with log-transformed data, as proportion measurements are restricted to positive values. Calculation for the random-effects estimate CI was based on the Hartung and Knapp method (Knapp & Hartung, 2003). For mean score endpoints, meta-analyses for estimating aggregate mean values were performed using log-transformed means, with 500 bootstrap replicates to calculate the prediction intervals. Forest plots were used to present the prevalence for each subgroup and the aggregated prevalence estimates. For covariate analysis, a p-value of <0.05 was considered as statistically significant.

The heterogeneity across studies was assessed using I^2 statistics, with thresholds of 25% or below representing low heterogeneity, between 25% and 50% representing medium heterogeneity, and 75% or above representing high heterogeneity (Higgins et al., 2003).

Publication bias was assessed through visual inspection of Begg's funnel plot (Begg & Mazumdar, 1994; Duval & Tweedie, 2000) and Egger's test for small study effects (Egger et al., 1997).

All analyses were conducted using R software (v4.3.2) (R Core Team). The "metaprop" and "metamean" functions from the meta package (v6.5-0) (Schwarzer, 2007) were used to estimate aggregate prevalence (Wang, 2023) and mean score, respectively. Covariates as potential risk factors and confounders were investigated using the "metareg" function and subgroup analysis.

Ethics and Dissemination

No ethical approval was required because this study used data from previously published studies where informed consent was obtained by the original investigators. The systematic review was registered with PROSPERO (CRD42024555983).

RESULTS

Systematic Review

Study Characteristics

A total of 1,632 potentially relevant citations were retrieved on March 28, 2024, from the initial search of the three databases, using search terms from the pre-specified search strategy (Supplemental Table 2). After removing duplicate citations from databases, a review of the abstracts and available full text was conducted. Additionally, one relevant citation (Lau et al., 2012) was identified through reference list screening and included in the final dataset.

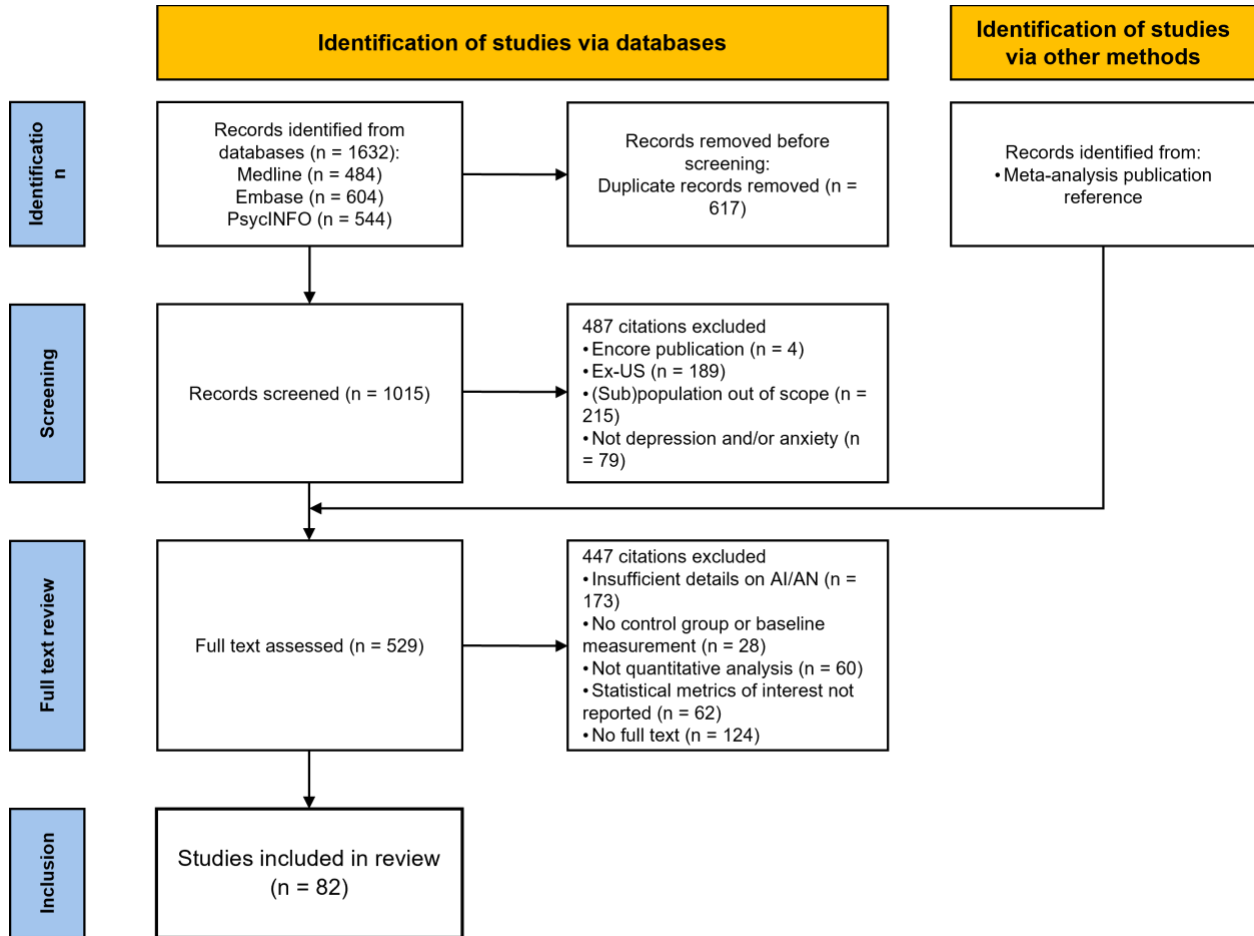
In total, 82 citations with data on depression and/or anxiety prevalence or mean score data were selected for inclusion in the meta-analysis dataset (Supplemental Table 3). A flow chart detailing the screening and exclusion process is displayed in Figure 1. Of the 82 citations, 65 (79%) were cross-sectional in study design.

In the meta-analysis dataset, 77 citations reported depression data, 15 citations reported anxiety data, and 4 citations reported depression and anxiety prevalence data together but did not discriminate between the two conditions. Specifically, out of the 82 citations,

- 63 citations reported depression data only
- 2 citations reported anxiety data only

- 3 citations reported depression + anxiety data together without discrimination between the two conditions
- 13 citations reported both depression and anxiety data but as separate conditions
- 1 citation reported depression data alone and depression + anxiety data together without discrimination between the two conditions

Figure 1. Flow chart of database and analysis data



Note: AI/AN=American Indian/Alaska Native, EX-US=outside of the United States.

Supplemental Table 4 displays the summary statistics of the study covariates of interest including publication year, percent of male study participants, and mean age as continuous variables, as well as geographical region and geographical setting as categorical variables. The publication year ranged from 1976 to 2024. The mean age, rather than the median age of the study participants, was more likely to be reported (49 vs. 3 studies). The distribution of male participants was bimodal (Supplemental Figure 1), with seven studies including only female participants (i.e.,

0% males). In addition, low to moderate correlation (correlation coefficient < 50%) existed between the continuous variables (Supplemental Figure 1). Among the categorical variables, the most represented geographical region was the Northern Plains (29.3%), while 28.0% of studies either spanned multiple regions or had missing information regarding geographical region. The reservation setting was the most prevalent, representing 35.4% of the studies, with 41.5% of the studies conducted at multiple geographical settings or lacking geographical setting information. Studies conducted on reservations were primarily located in the Northern Plains or Southwest, whereas studies conducted in rural areas were mostly located in the Southeast, specifically in North Carolina (Supplemental Table 5).

No imputation of the covariates was performed due to data heterogeneity in a relatively small analysis dataset. The analysis dataset with the list of citations is provided in the [Supplemental File](#).

Quality Assessment

The 82 citations in the analysis dataset were assessed for reporting quality using a checklist for cross-sectional studies (University of Bern Institute of Social and Preventive Medicine, n.d.), with individual scores for each citation detailed in Supplemental Table 6. The quality assessment revealed that 68 out of 82 citations (82.9%) lacked information on missing data, and 30 out of 82 citations (36.6%) did not disclose a funding source for the study. Notably, 22 of the 82 citations were dissertations in fulfillment of degree programs. These dissertations were less likely to identify funding sources for their projects but were more likely to address missing data or include raw data in an appendix section.

Meta-analysis of Depression Endpoints

Depression prevalence was initially the primary outcome measure assessed using meta-analysis. Due to limited prevalence data, however, depression mean scores were also analyzed drawing on the mean score data from the systematic review.

Prevalence

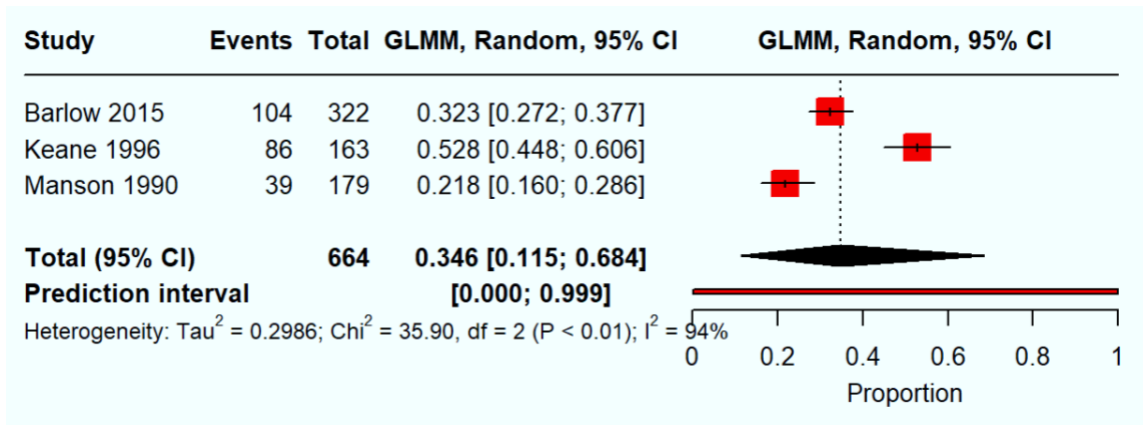
In the analysis dataset, depression prevalence was most frequently measured using the 20-item Center for Epidemiological Studies Depression (CES-D) scale (Radloff, 1991). Three studies, with a total sample of 664 participants, reported prevalence data based on the CES-D using a cutoff score of 16 (out of a maximum of 60), as cutoff for clinical significance for depression. Of the three studies, the population and setting included teen mothers in reservation communities in the

Southwest region (Barlow et al., 2015), students at a tribally administered secondary boarding school of undisclosed location (Keane et al., 1996), and students at a tribal boarding school in a rural area of southeastern United States (Manson et al., 1990). From the meta-analysis, the aggregate point prevalence of depression of the three studies was 34.6% (95% CI: 11.5 to 68.4%, $\tau^2 = 0.299$, $I^2=94%$) (Figure 2). There was a statistically significant, high-level of heterogeneity among the studies ($p < 0.01$), but the percent of male participants and publication year were not statistically significant covariates. There were insufficient data to test the impact of other covariates of interest.

The Children’s Depression Index (CDI) was the second most commonly used tool for measuring depression prevalence, with a 27-item format (Kovacs, 1985). In two studies totaling 365 participants, depression prevalence was calculated based on CDI scores using a clinical cutoff score of 19 or 20 (out of a maximum of 54) for depression. Meta-analysis estimated an aggregate point prevalence of 14.5% (95% CI: 2.5-52.9%, $\tau^2 = 0$, $I^2=22%$) for depression (Figure 3). In contrast to CES-D, the heterogeneity among CDI-based studies was low and not statistically significant ($p = 0.26$), and covariate analysis was not performed due to the limited number of studies.

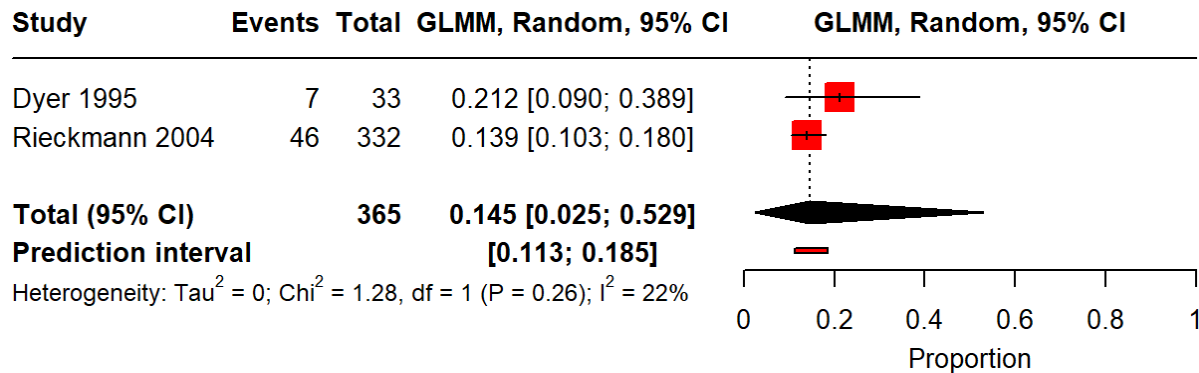
A comprehensive list of all instruments used across the studies can be found in the [Supplemental File](#) (Supplemental Table 3).

Figure 2. Forest plot of depression prevalence based on the Center for Epidemiologic Studies Depression (CES-D) scale



Note: CI = confidence interval, df = degrees of freedom, GLMM = generalized linear mixed model. The vertical dash is the observed prevalence for the study, the horizontal whisker is the 95% CI, and the size of the squares is proportional to the study weight. The vertical dashed line is the aggregate prevalence, and the width of the diamond represents the CI of the aggregate prevalence.

Figure 3. Forest plot of depression prevalence based on the Children’s Depression Inventory (CDI)



Note: CI = confidence interval, df = degrees of freedom, GLMM = generalized linear mixed model. The vertical dash is the observed prevalence for the study, the horizontal whisker is the 95% CI, and the size of the squares is proportional to the study weight. The vertical dashed line is the aggregate prevalence, and the width of the diamond represents the CI of the aggregate prevalence.

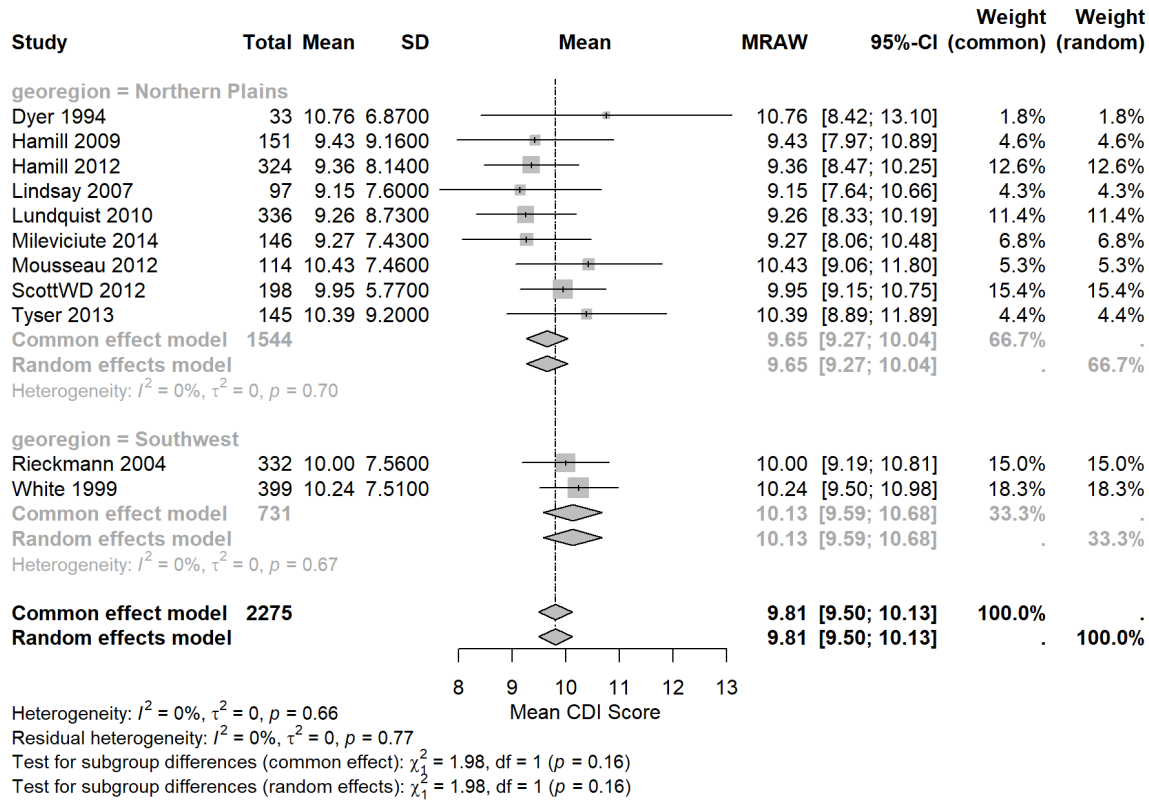
Mean Score

Mean score data from screening or diagnostic tests for depression were more widely available than prevalence data in the systematic review, with the CDI (27 items) and CES-D (20 items) being the most commonly used instruments to measure depression. As such, meta-analysis was conducted on outcome measurements from these two instruments to assess aggregate mean scores for depression.

Children’s Depression Index (CDI). The distribution of CDI mean scores from 2,275 participants across 11 studies is shown in Supplemental Figure 2, with scores ranging from 9.15 to 10.76 out of a possible score of 54. Meta-analysis produced an aggregate mean score of 9.81 (95% CI: 9.50-10.1, $\tau^2 = 0$, $I^2=0\%$), with no statistically significant heterogeneity among the studies ($p = 0.66$) (Figure 4).

Out of the 11 studies, nine were conducted among AI/AN populations in the Northern Plains and two in the Southwest. Stratified subgroup analysis estimated an aggregate mean score of 9.65 (95% CI: 9.27 to 10.0) for the Northern Plains and 10.1 (95% CI: 9.59 to 10.7) for the Southwest (Figure 4). This analysis revealed a strong overlap in the aggregate mean scores between the two geographical regions; however, the difference was not statistically significant ($p = 0.16$). Regression analysis revealed that publication year, percent of male participants, and mean age of participants were not statistically significant covariates with p-values of 0.147, 0.151, and 0.251, respectively. Therefore, no covariates were included in the final meta-analysis model for CDI mean score.

Figure 4. Forest plot of Children's Depression Inventory (CDI) mean score for depression and stratified by geographic region (Northern Plains and Southwest)

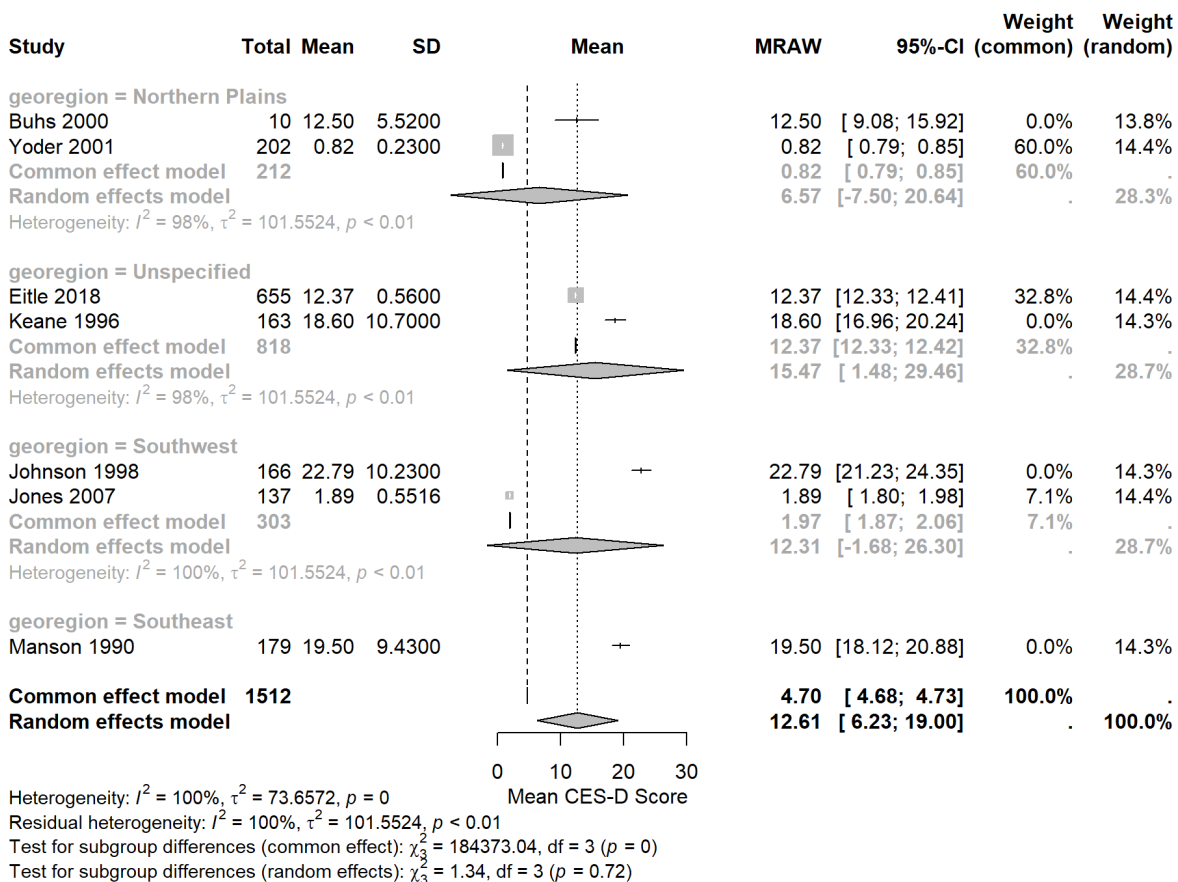


Note: CI = confidence interval, df = degrees of freedom, MRAW = raw or untransformed mean that is pooled for the summary measures, SD = standard deviation. The vertical dash is the observed mean score for the study, the horizontal whisker is the 95% CI, and the size of the squares is proportional to the study weight. The vertical dashed line is the aggregate mean score, and the width of the diamond represents the CI of the aggregate mean score.

The funnel plot indicated a lack of publication bias from small studies (Supplemental Figure 3), and the Egger’s test was not statistically significant for asymmetry ($p = 0.967$). Influence analysis detected no outlier studies (Supplemental Figure 4).

Center for Epidemiologic Studies Depression (CES-D). The CES-D mean scores were reported for 1,512 participants across seven studies, with scores ranging from 0.82 to 22.8 (Supplemental Figure 5). The meta-analysis estimated an aggregate mean score of 12.6 (6.23 to 19.0, $\tau^2 = 73.7$, $I^2=100\%$), as shown in Figure 5. With fewer than 10 studies, the Egger’s test was not conducted.

Figure 5. Forest plot of Center for Epidemiologic Studies Depression (CES-D) scale mean scores for depression and stratified by geographic region (Northern Plains, Southeast, Southwest, Unspecified)



Note: CI = confidence interval, df = degrees of freedom, MRAW = raw or untransformed mean that is pooled for the summary measures, SD = standard deviation, Unspecified = multiple or unknown. The vertical dash is the observed mean score for the study, the horizontal whisker is the 95% CI, and the size of the squares is proportional to the study weight. The vertical dashed line is the aggregate mean score, and the width of the diamond represents the CI of the aggregate mean score.

The seven studies represented four geographical regions. Based on subgroup analysis, the difference in CES-D mean scores was statistically significant among geographical regions ($p < 0.0001$), as indicated in Figure 5. Stratified subgroup analysis estimated an aggregated mean score of 6.57 between the two studies conducted in the Northern Plains and an aggregated mean score of 15.47 (95% CI: 1.48 to 29.46) among the two studies with multiple/unspecified geographic location. These scores contrasted the mean scores of 12.3 and 19.5 from two studies conducted in the Southeast and one study conducted in the Southwest regions, respectively. Subgroup analysis was also performed using geographical setting categories of reservation, rural, urban, and unspecified/multiple settings. Although the difference in CES-D mean scores among

geographical setting categories was statistically significant ($p < 0.0001$), data up to only three studies were included in each category (Supplemental Figure 6). Among the other covariates investigated, publication year and percent of male participants were not statistically significant (p -values 0.246 and 0.146, respectively).

Anxiety

Anxiety prevalence and mean score data were available in 15 citations from the systematic review as measured across 10 different instruments. Among the 15 citations, 4 had prevalence data and 12 had mean score data (i.e., one citation had both prevalence and mean score data). Three out of the 15 studies assessed anxiety with unspecified measurement tools. One study was conducted solely in Alaska (Harvey et al., 1976). The Generalized Anxiety Disorder 7-item (GAD-7) scale (Spitzer et al., 2006) was the most frequently used instrument, with one citation reporting anxiety prevalence data and two citations reporting mean score data. In the study by D'Amico and colleagues, 18% of AI/AN adolescents in urban areas reported experiencing clinically significant anxiety in 2020 during the COVID-19 pandemic (D'Amico et al., 2020). Due to minimal data reporting anxiety prevalence or mean score using GAD-7, no meta-analysis was conducted for anxiety.

Combined Depression and Anxiety

Four citations in the systematic review reported the prevalence or mean scores for combined depression and anxiety without distinguishing between the two conditions. Due to the lack of consistent measurement tools, no meta-analysis was performed on these combined outcomes.

DISCUSSION

This study aimed to examine variations in the prevalence of anxiety and depression among AI/AN adolescents, with a particular focus on the impact of geographical region as a potential driver of these disparities. To our knowledge, this is the first meta-analysis to provide aggregate prevalence estimates and mean scores for depression in AI/AN adolescents. As such, this study offers a foundational understanding of mental health within this population.

The systematic review confirmed that data on anxiety prevalence were minimal, while depression data were limited. As such, additional meta-analyses were conducted on depression

mean scores, which were more frequently reported than prevalence data. However, due to the large variations in measurement tools used across studies, only small subsets of studies were selected for the meta-analysis. Meta-analysis revealed distinct aggregate prevalence estimates for depression, with 14.5% based on the 27-item CDI from two studies and 34.6% on the 20-item CES-D from three studies. The CDI was developed to evaluate depression symptoms in children and adolescents, where age is a significant factor in depression scores, whereas the CES-D, originally designed for the general adult population, has been validated for use among adolescents across certain racial and ethnic groups, including Native Americans (Heo et al., 2018; Wiegman et al., 1994). Given the varying sensitivity and specificity of these tools (US Preventive Services Task Force et al., 2022), differences in prevalence estimates between CDI and CES-D methods are expected. Compared to previously reported CES-D prevalence estimates from other adolescent populations in the United States, the 34.6% aggregate prevalence estimate for AI/AN adolescents is higher than the prevalence reported in the National Longitudinal Study of Adolescent Health (28.7%) (Rushton et al., 2002), lower than the prevalence reported for Black adolescents living in urban public housing (42.4%) (Lu et al., 2017), but similar to the prevalence observed among White adolescents in rural areas (34%) (Peden et al., 2005). IHS reported depression prevalence estimates for AI/AN adolescent patients, using diagnosis based on various tools in electronic health records, and found estimates ranged between 14.42 and 130.94 per 10,000 AI/AN adolescent patients (IHS, 2018). Unsurprisingly, these diagnostic prevalence estimates are lower when contrasted to the screening depression prevalence estimates in the current analysis.

Similar to prevalence estimates, mean scores measured using CES-D also showed large variability (0.82-22.8) among the seven studies included in the meta-analysis. The limited and heterogeneous nature of the data were less likely to provide accurate aggregate estimates from the meta-analyses for the three prevalence estimates. Mean scores measured using CDI (27 items) were less heterogeneous, and it was also the most prevalent outcome measure from the systematic review. Based on the meta-analysis, the aggregate CDI mean score for AI/AN adolescents is 9.81, which is below the clinical significance cutoff of 16 for mild severity of depression among adolescents but is higher than their White, Asian, Black, and Latino counterparts, whose CDI mean scores ranged from 5.13 to 8.31 in a large, racially and ethnically diverse study conducted in the United States (Vaughn-Coaxum et al., 2016). The trend of elevated depression mean score is also consistent with that of the higher rate of suicide ideation observed among AI/AN adolescents compared to other racial and ethnic groups (Baiden et al., 2020).

The AI/AN population is geographically diverse. The 82 citations included in the meta-analysis dataset encompass data from all five geographical regions (i.e., Northern Plains, Northwest, Southeast, Southern Plains, Southwest). However, large percentages of the studies either spanned multiple geographical regions/settings or had missing region/setting information. Stratified subgroup analysis used to investigate potential covariate effects indicated that geographical region (Northern Plains vs. Southeast vs. Southwest vs. multiple/unspecified) had a statistically significant impact in the estimation of CES-D mean score. There was a large range in the model estimated mean scores among geographical regions, from 6.57 in the Northern Plains to 19.5 in the Southeast, probably because the data are limited and overly heterogeneous. Thus, the results were not likely to be reliable.

None of the other tested covariates showed statistical significance for any of the four measured outcomes, even for subgroups that are known to have different depression prevalence estimates. One source of this discrepancy could be attributed to ecological bias, where a risk factor (or lack of) identified at the summary-level is not detected at the individual-level (Greenland & Morgenstern, 1989). For example, female adolescents are known to have higher prevalence of depression compared to males (NIMH, 2023). However, the percent of male study participants was not a statistically significant covariate in the meta-analyses. This could be due to the reduced granularity of the summary-level data, where the majority of the studies included for the meta-analysis had a similar percentage of male participants (around 50%). The inability to identify known covariates in the meta-analysis also could be caused by the fairly large number of missing values in covariates, which limited the statistical power of the analysis. Furthermore, only a few covariate values were reported at the summary-level from each study, and potentially more impactful covariates exist but were unavailable in this meta-analysis. Publication year was available for all studies included in the analysis and ranged from 1976 to 2024. A small portion of the studies in the analysis dataset (12 out of 82 studies, 14.6%) were published after 2020. Although publication year was not a statistically significant covariate, it is unknown if the COVID-19 pandemic lockdown would have an independent impact on the depression or anxiety prevalence or mean scores.

Public Health Implications

This study provides comprehensive evidence from published results through a systematic review and a meta-analysis to identify, evaluate, and summarize the prevalence of anxiety and

depression among AI/AN adolescents. The evidence generated from this study contributes to the knowledge base of mental health issues among AI/AN adolescents. However, the limited number of studies and participants included in this systematic review and meta-analysis restricts the generalizability of the results. This limitation emphasizes the need for additional data and primary studies to more accurately determine the prevalence, variations, and risk factors of depression and anxiety specific to AI/AN adolescents, particularly across diverse geographical regions and settings. Comparable research on Indigenous adolescents in Canada estimated a pooled prevalence of mood and/or anxiety disorders at less than 2.9% (Owais et al., 2022). In response, the Canadian government recently proposed \$630.2 million in mental health funding over two years for the First Nations and Inuit people (Crown-Indigenous Relations and Northern Affairs Canada, 2024) to address health inequities. In contrast, while mental health programs exist for the AI/AN populations in the United States through IHS (IHS, n.d.-b), chronic and severe underfunding has perpetuated a treatment gap (Warne & Frizzell, 2014), especially in rural and remote reservation areas. Addressing mental health disparities among AI/AN adolescents will require a dual approach: increased investment in mental health care resources and the collection of higher quality data. These approaches are essential for developing culturally appropriate, evidence-based interventions that can reduce mental health disparities and promote positive well-being among AI/AN adolescents.

REFERENCES

- Alcántara, C., & Gone, J. P. (2007). Reviewing suicide in Native American communities: Situating risk and protective factors within a transactional-ecological framework. *Death Studies*, 31(5), 457–477. <https://doi.org/10.1080/07481180701244587>
- American Academy of Pediatrics. (2023, September 29). Indigenous Health Special Interest Group. <https://www.aap.org/en/patient-care/native-american-child-health/Indigenous-health-special-interest-group/#>
- American Medical Association. (2021, June 16). AMA adopts policy to address increases in youth suicide and save lives. <https://www.ama-assn.org/press-center/press-releases/ama-adopts-policy-address-increases-youth-suicide-and-save-lives>

- American Psychological Association Services Inc. (2023, March 8). Promoting the mental health of Native American children. <https://www.apaservices.org/advocacy/news/mental-health-native-american-children>
- Asher BlackDeer, A., & Patterson Silver Wolf, D. A. (2020). Evidence Mapping: Interventions for American Indian and Alaska Native Youth Mental Health. *Journal of Evidence-Based Social Work* (2019), 17(1), 49–62. <https://doi.org/10.1080/26408066.2019.1624237>
- Automeris LLC. (n.d.). Extract data from charts. Retrieved June 24, 2024, from <https://automeris.io/v4/>
- Baiden, P., LaBrenz, C. A., Asiedua-Baiden, G., & Muehlenkamp, J. J. (2020). Examining the intersection of race/ethnicity and sexual orientation on suicidal ideation and suicide attempt among adolescents: Findings from the 2017 Youth Risk Behavior Survey. *Journal of Psychiatric Research*, 125, 13–20. <https://doi.org/10.1016/j.jpsychires.2020.02.029>
- Barlow, A., Mullany, B., Neault, N., Goklish, N., Billy, T., Hastings, R., Lorenzo, S., Kee, C., Lake, K., Redmond, C., Carter, A., & Walkup, J. T. (2015). Paraprofessional-delivered home-visiting intervention for American Indian teen mothers and children: 3-year outcomes from a randomized controlled trial. *The American Journal of Psychiatry*, 172(2), 154–162. <https://doi.org/10.1176/appi.ajp.2014.14030332>
- Begg, C. B., & Mazumdar, M. (1994). Operating characteristics of a rank correlation test for publication bias. *Biometrics*, 50(4), 1088–1101.
- Borenstein, M., Hedges, L. V., Higgins, J. P., & Rothstein, H. R. (2010). A basic introduction to fixed-effect and random-effects models for meta-analysis. *Research Synthesis Methods*, 1(2), 97–111. <https://doi.org/10.1002/jrsm.12>
- Chen, T., Li, W., Zambarano, B., & Klompas, M. (2022). Small-area estimation for public health surveillance using electronic health record data: Reducing the impact of underrepresentation. *BMC Public Health*, 22(1), 1515. <https://doi.org/10.1186/s12889-022-13809-2>
- Cheref, S., Benoit, J. S., & Walker, R. L. (2019). Refining psychological, substance use, and sociodemographic predictors of suicide ideation and attempts in a national multiethnic sample of adults, 2008–2013. *Journal of Nervous and Mental Disease*, 207(8), 675–682. <https://doi.org/10.1097/NMD.0000000000001026>

- Cochrane UK. (2023, July 19). Meta-analysis: What, Why, and How. <https://uk.cochrane.org/news/meta-analysis-what-why-and-how>
- Crown-Indigenous Relations and Northern Affairs Canada. (2024, July 24). Health. <https://www.rcaanc-cirnac.gc.ca/eng/1524499024614/1557512659251>
- D'Amico, E. J., Palimaru, A. I., Dickerson, D. L., Dong, L., Brown, R. A., Johnson, C. L., Klein, D. J., & Troxel, W. M. (2020). Risk and resilience factors in urban American Indian and Alaska Native youth during the coronavirus pandemic. *American Indian Culture and Research Journal*, 44(2), 21–48.
- Duval, S., & Tweedie, R. (2000). Trim and fill: A simple funnel-plot-based method of testing and adjusting for publication bias in meta-analysis. *Biometrics*, 56(2), 455–463. <https://doi.org/10.1111/j.0006-341x.2000.00455.x>
- Egger, M., Davey Smith, G., Schneider, M., & Minder, C. (1997). Bias in meta-analysis detected by a simple, graphical test. *BMJ (Clinical research ed.)*, 315(7109), 629–634. <https://doi.org/10.1136/bmj.315.7109.629>
- Ferrari, A. J., Charlson, F. J., Norman, R. E., Patten, S. B., Freedman, G., Murray, C. J., Vos, T., & Whiteford, H. A. (2013). Burden of depressive disorders by country, sex, age, and year: Findings from the global burden of disease study 2010. *PLoS Medicine*, 10(11), e1001547. <https://doi.org/10.1371/journal.pmed.1001547>
- Gone, J. P., & Trimble, J. E. (2012). American Indian and Alaska Native mental health: Diverse perspectives on enduring disparities. *Annual Review of Clinical Psychology*, 8, 131–160. <https://doi.org/10.1146/annurev-clinpsy-032511-143127>
- Goodkind, J. R., Ross-Toledo, K., John, S., Hall, J. L., Ross, L., Freeland, L., Coletta, E., Becenti-Fundark, T., Poola, C., Begay-Roanhorse, R., & Lee, C. (2010). Promoting healing and restoring trust: Policy recommendations for improving behavioral health care for American Indian/Alaska Native adolescents. *American Journal of Community Psychology*, 46(3-4), 386–394. <https://doi.org/10.1007/s10464-010-9347-4>
- Grandbois D. (2005). Stigma of mental illness among American Indian and Alaska Native nations: historical and contemporary perspectives. *Issues in Mental Health Nursing*, 26(10), 1001–1024. <https://doi.org/10.1080/01612840500280661>

- Greenland, S., & Morgenstern, H. (1989). Ecological bias, confounding, and effect modification. *International Journal of Epidemiology*, 18(1), 269–274. <https://doi.org/10.1093/ije/18.1.269>
- Han, B., & Eskin, E. (2011). Random-effects model aimed at discovering associations in meta-analysis of genome-wide association studies. *American Journal of Human Genetics*, 88(5), 586–598. <https://doi.org/10.1016/j.ajhg.2011.04.014>
- Harvey, E. B., Gazay, L., & Samuels, B. (1976). Utilization of a psychiatric-social work team in an Alaskan native secondary boarding school. A five-year review. *Journal of the American Academy of Child Psychiatry*, 15(3), 558–574. [https://doi.org/10.1016/s0002-7138\(09\)61629-0](https://doi.org/10.1016/s0002-7138(09)61629-0)
- Heo, E. H., Choi, K. S., Yu, J. C., & Nam, J. A. (2018). Validation of the Center for Epidemiological Studies Depression Scale among Korean adolescents. *Psychiatry investigation*, 15(2), 124–132. <https://doi.org/10.30773/pi.2017.07.19>
- Higgins, J. P., Thompson, S. G., Deeks, J. J., & Altman, D. G. (2003). Measuring inconsistency in meta-analyses. *BMJ (Clinical research ed.)*, 327(7414), 557–560. <https://doi.org/10.1136/bmj.327.7414.557>
- Higgins, J. & Green, S. (2009). *Cochrane handbook for systematic reviews of interventions*. <https://doi.org/10.1002/9780470712184>
- Indian Health Service. (2018, March). Report on Behavioral Health, 2018 Edition. https://www.ihs.gov/sites/dps/themes/responsive2017/display_objects/documents/IHS2018BehavioralHealth.pdf
- Indian Health Service. (n.d.-a). Chapter 1 - Eligibility for Services. Retrieved June 24, 2024, from <https://www.ihs.gov/ihm/pc/part-2/chapter-1-eligibility-for-services/>
- Indian Health Service. (n.d.-b). Mental Health. Retrieved June 24, 2024, from <https://www.ihs.gov/mentalhealth/>
- Joanna Briggs Institute. (n.d.). JBI Manual for Evidence Synthesis: 2024 Edition. Retrieved June 24, 2024, from <https://jbi-global-wiki.refined.site/space/MANUAL>

- Ka'apu, K., & Burnette, C. E. (2019). A Culturally Informed Systematic Review of Mental Health Disparities Among Adult Indigenous Men and Women of the USA: What is known?. *British Journal of Social Work*, 49(4), 880–898. <https://doi.org/10.1093/bjsw/bcz009>
- Keane, E. M., Dick, R. W., Bechtold, D. W., & Manson, S. M. (1996). Predictive and concurrent validity of the Suicidal Ideation Questionnaire among American Indian adolescents. *Journal of Abnormal Child Psychology*, 24(6), 735–747. <https://doi.org/10.1007/BF01664737>
- Knapp, G., & Hartung, J. (2003). Improved tests for a random effects meta-regression with a single covariate. *Statistics in Medicine*, 22(17), 2693–2710. <https://doi.org/10.1002/sim.1482>
- Kovacs M. (1985). The Children's Depression, Inventory (CDI). *Psychopharmacology Bulletin*, 21(4), 995–998.
- Lau, M., Lin, H., & Flores, G. (2012). Racial/ethnic disparities in health and health care among U.S. adolescents. *Health Services Research*, 47(5), 2031–2059. <https://doi.org/10.1111/j.1475-6773.2012.01394.x>
- Lu, W., Lindsey, M. A., Irsheid, S., & Nebbitt, V. E. (2017). Psychometric properties of the CES-D among Black adolescents in public housing. *Journal of the Society for Social Work and Research*, 8(4), 595–619. <https://doi.org/10.1086/694791>
- Manson, S. M., Ackerson, L. M., Dick, R. W., Baron, A. E., & Fleming, C. M. (1990). Depressive symptoms among American Indian adolescents: Psychometric characteristics of the Center for Epidemiologic Studies Depression Scale (CES-D). *Psychological Assessment: A Journal of Consulting and Clinical Psychology*, 2(3), 231–237. <https://doi.org/10.1037/1040-3590.2.3.231>
- Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., Shekelle, P., Stewart, L. A., & PRISMA-P Group. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews*, 4(1), 1. <https://doi.org/10.1186/2046-4053-4-1>
- Moon, S. S., Boyas, J., & Kim, Y. K. (2020). Using a classification tree modeling approach to predict cigarette use among adolescents in the United States. *Substance Use & Misuse*, 55(1), 12–22. <https://doi.org/10.1080/10826084.2019.1653323>

- National Alliance on Mental Health. (n.d.). Indigenous. Retrieved June 24, 2024, from <https://www.nami.org/Your-Journey/Identity-and-Cultural-Dimensions/Indigenous>
- National Institute of Mental Health. (2023, July). Major depression. Retrieved June 24, 2024, from <https://www.nimh.nih.gov/health/statistics/major-depression>
- National Institute of Mental Health. (2024, December). Depression. Retrieved June 24, 2024, from <https://www.nimh.nih.gov/health/topics/depression>
- National Institute of Mental Health. (n.d.). Any anxiety disorder. Retrieved June 24, 2024, from <https://www.nimh.nih.gov/health/statistics/any-anxiety-disorder>
- Novins, D. K., Beals, J., Roberts, R. E., & Manson, S. M. (1999). Factors associated with suicide ideation among American Indian adolescents: Does culture matter?. *Suicide & Life-Threatening Behavior*, 29(4), 332–346.
- Owais, S., Tsai, Z., Hill, T., Ospina, M. B., Wright, A. L., & Van Lieshout, R. J. (2022). Systematic review and meta-analysis: First Nations, Inuit, and Métis youth mental health. *Journal of the American Academy of Child and Adolescent Psychiatry*, 61(10), 1227–1250. <https://doi.org/10.1016/j.jaac.2022.03.029>
- Peden, A. R., Reed, D. B., & Rayens, M. K. (2005). Depressive symptoms in adolescents living in rural America. *The Journal of Rural Health*, 21(4), 310–316. <https://doi.org/10.1111/j.1748-0361.2005.tb00100.x>
- R Core Team (2024). R: A Language and Environment for Statistical Computing. R Foundation for Statistical Computing, Vienna, Austria. <https://www.R-project.org/>
- Radloff L. S. (1991). The use of the Center for Epidemiologic Studies Depression Scale in adolescents and young adults. *Journal of Youth and Adolescence*, 20(2), 149–166. <https://doi.org/10.1007/BF01537606>
- Rushton, J. L., Forcier, M., & Schectman, R. M. (2002). Epidemiology of depressive symptoms in the National Longitudinal Study of Adolescent Health. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41(2), 199–205. <https://doi.org/10.1097/00004583-200202000-00014>

- Sánchez-Rivera, A.I., Jacobs P., & Spence, C. (2023, October 3). A Look at the Largest American Indian and Alaska Native Tribes and Villages in the Nation, Tribal Areas and States. United States Census Bureau. <https://www.census.gov/library/stories/2023/10/2020-census-dhc-a-aian-population.html>
- Schwarzer, G. (2007). Meta: An R package for meta-analysis. *R News*, 7:40–45. <https://journal.r-project.org/articles/RN-2007-029/RN-2007-029.pdf>
- Shamseer, L., Moher, D., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., Shekelle, P., Stewart, L. A., & PRISMA-P Group (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ (Clinical research ed.)*, 350, g7647. <https://doi.org/10.1136/bmj.g7647>
- Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: The GAD-7. *Archives of Internal Medicine*, 166(10), 1092–1097. <https://doi.org/10.1001/archinte.166.10.1092>
- Storck, M., Beal, T., Bacon, J. G., & Olsen, P. (2009). Behavioral and mental health challenges for indigenous youth: research and clinical perspectives for primary care. *Pediatric Clinics of North America*, 56(6), 1461–1479. <https://doi.org/10.1016/j.pcl.2009.09.015>
- Tyser, J., Scott, W. D., Readdy, T., & McCrea, S. M. (2014). The role of goal representations, cultural identity, and dispositional optimism in the depressive experiences of American Indian youth from a Northern Plains tribe. *Journal of Youth and Adolescence*, 43(3), 329–342. <https://doi.org/10.1007/s10964-013-0042-2>
- United States Census Bureau. (2025, January 21). The American Indian and Alaska Native Population. <https://www.census.gov/history/pdf/c2010br-10.pdf>
- United States Department of Health and Human Services, Office of Minority Health. (2025, September). American Indian/Alaska Native Health. <https://minorityhealth.hhs.gov/american-indianalaska-native-health>

- US Preventive Services Task Force, Mangione, C. M., Barry, M. J., Nicholson, W. K., Cabana, M., Chelmsow, D., Coker, T. R., Davidson, K. W., Davis, E. M., Donahue, K. E., Jaén, C. R., Kubik, M., Li, L., Ogedegbe, G., Pbert, L., Ruiz, J. M., Silverstein, M., Stevermer, J., & Wong, J. B. (2022). Screening for depression and suicide risk in children and adolescents: US Preventive Services Task Force Recommendation Statement. *JAMA*, 328(15), 1534–1542. <https://doi.org/10.1001/jama.2022.16946>
- University of Bern Institute of Social and Preventive Medicine. (n.d.). STROBE Checklists. Retrieved June 24, 2024, from <https://www.strobe-statement.org/checklists/>
- Vaughn-Coaxum, R. A., Mair, P., & Weisz, J. R. (2016). Racial/ethnic differences in youth depression indicators: An item response theory analysis of symptoms reported by White, Black, Asian, and Latino youths. *Clinical Psychological Science*, 4(2), 239–253. <https://doi.org/10.1177/2167702615591768>
- Wang, N. (2023). Conducting Meta-analyses of Proportions in R. *Journal of Behavioral Data Science*, 3(2), 64-126. <https://doi.org/10.35566/jbds/v3n2/wang>
- Warne, D., & Frizzell, L. B. (2014). American Indian health policy: Historical trends and contemporary issues. *American Journal of Public Health*, 104(Suppl 3), S263–S267. <https://doi.org/10.2105/AJPH.2013.301682>
- Whitbeck, L. B. (2011). The beginnings of mental health disparities: Emergent mental disorders among indigenous adolescents. In G. Carlo, L. J. Crockett, & M. A. Carranza (Eds.), *Health disparities in youth and families: Research and applications* (pp. 121–149). Springer Science + Business Media. https://doi.org/10.1007/978-1-4419-7092-3_6
- Wiegman Dick, R., Beals, J., Keane, E. M., & Manson, S. M. (1994). Factorial structure of the CES-D among American Indian adolescents. *Journal of Adolescence*, 17(1), 73-79. <https://doi.org/10.1006/jado.1994.1007>
- World Health Organization. (n.d.). Adolescent health. Retrieved June 24, 2024, from https://www.who.int/health-topics/adolescent-health#tab=tab_1
- Yu, M., & Whitbeck, L. B. (2016). A prospective, longitudinal study of cigarette smoking status among North American Indigenous adolescents. *Addictive Behaviors*, 58, 35–41. <https://doi.org/10.1016/j.addbeh.2016.02.007>

ACKNOWLEDGEMENTS

The authors would like to express their appreciation to Emma Shaw, Library Manager and Liaison Librarian at Imperial College London, for providing input on the systematic review search strategy, and to Kirk Greenway, Director at the Division of Program Statistics of Indian Health Service, for explaining the data in the Report on Behavioral Health.

CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest.

FUNDING

The authors have no funding to report.

AUTHOR INFORMATION

Phyllis Chan, PhD, was a Global Master of Public Health student in the School of Public Health at the Imperial College London in London, UK.

Abdelrahman M. Makram, MBBCh, was a Global Master of Public Health student in the School of Public Health at the Imperial College London in London, UK.

Valentín Quiroz de la Sierra (Yo'eme), PhD, is a Postdoctoral Fellow at the Center for Indigenous Health at Johns Hopkins University, Baltimore, Maryland.

Samantha Alvarez Madrazo, PhD, is a Senior Teaching Fellow in the School of Public Health at the Imperial College London, London, UK.

Nosha Assareh, PhD, is a Research Associate in the School of Public Health at the Imperial College London in London, UK.

Nick Jayanth, MSc, is a Teaching Fellow in the School of Public Health at the Imperial College London in London, UK.

Mary Cwik, PhD, is a Senior Scientist at the Center for Indigenous Health at Johns Hopkins University, Baltimore, Maryland.

Understanding the Drivers of Perceived PrEP Stigma among Indigenous People in the United States

Monica M. Desjardins, MPH (Diné), Jessica Leston, MPH (Tsimshian), Erica N. Browne, MS, Sarah M. Hatcher, PhD, Brigg Reilley, MPH, Ashley Hoover, MPH, Andrew Freeman, BA, Matthew Bensen, MA, Bob Henne, BS, and Sarah T. Roberts, PhD

***Abstract:** Previous research has demonstrated that pre-exposure prophylaxis (PrEP) stigma serves as a common barrier to PrEP use across racial, ethnic, and sexual minority groups in the United States; however, there is a deficit in research focused on Indigenous populations. Therefore, the objective of this study was to identify drivers of PrEP stigma among Indigenous people. A cross-sectional survey was administered to examine PrEP knowledge, attitudes, and perceived barriers to use among Indigenous people in the United States, including PrEP stigma and the following hypothesized drivers: stigma towards drug use, 2SLGBTQ+ identity, and HIV; experienced discrimination; and medical mistrust. Participants reported that people in their communities associate PrEP use with drug use, 2SLGBTQ+ identities, living with HIV, and having multiple sexual partners. They also perceived high levels of stigma around these behaviors and identities in their communities and reported high levels of experienced discrimination and medical mistrust. Higher levels of each hypothesized driver were significantly associated with higher levels of perceived PrEP stigma among the respondents. The results generated from this study provide recommendations for interventions that aim to reduce the influence of these drivers on PrEP stigma.*

INTRODUCTION

Indigenous¹ communities experience significant health disparities, including challenges related to HIV prevention and treatment. According to the Centers for Disease Control and Prevention data from 2022, the HIV incidence rate among American Indian/Alaska Native (AI/AN) people was twice the rate among White people, though lower than that of Black/African American, Hispanic/Latino, and multiracial populations (Centers for Disease and Control and Prevention, 2024). Historical trauma, colonization, and systemic inequities continue to impact health and healthcare access in Indigenous communities. These historical legacies are compounded by social, economic, and structural determinants of health, such as poverty, limited healthcare access, and the ongoing marginalization of Indigenous ways of knowing and healing (Walters et al., 2011). Addressing these complexities is vital in understanding the broader context of HIV-related disparities and reducing barriers to effective HIV prevention and treatment strategies in Indigenous communities.

Pre-exposure prophylaxis (PrEP) is a highly effective biomedical intervention (Baeten et al., 2012) that can greatly reduce HIV incidence in AI/AN populations. Yet, despite its promise, AI/AN people face inequitable access to PrEP. Structural racism, lack of culturally responsive healthcare services, and social stigmatization all act as barriers. Recent data highlights that AI/AN men who identify as part of sexual minority groups had 36% lower odds of using PrEP compared to their White counterparts, reflecting a deep-seated disparity (Whitfield et al., 2020).

For Indigenous communities, stigma surrounding PrEP use intersects with broader, culturally situated experiences of stigma, including the historical mistrust of Westernized medical systems, discrimination in healthcare, and stigmatization tied to sexual behavior, gender identity, and substance use (Leston et al., 2022). PrEP use itself is often viewed through a stigmatizing lens,

¹ We use the term “Indigenous” in this document to honor the original peoples of the lands and waters now known as the United States and its territories. We recognize that individuals and communities may identify with specific Tribal Nation names, cultural groups, or regional identities, and that terms such as American Indian, Alaska Native, Native Hawaiian, and Pacific Islander (NHPI) each carry distinct histories, meanings, and legal contexts. The use of “Indigenous” here is meant to be inclusive and respectful, while acknowledging the diversity, sovereignty, and self-determination of all Native peoples. In some instances, when referencing studies, reports, or data sources, we may use the terminology employed in the original source (e.g., American Indian/Alaska Native, Native Hawaiian, or other region-specific terms) to preserve the accuracy and context of the cited work. This reflects our commitment to accurate representation of source material.

seen as indicative of either HIV status or behaviors perceived as non-normative within both Indigenous and broader societal contexts (Elopre et al., 2018; Golub, 2018). Within AI/AN communities, this stigma is reinforced by post-colonial cultural mores around discussing sexual health and the historical marginalization of 2SLGBTQ+² individuals.

It is essential to contextualize elements of PrEP stigma through a framework of health equity. PrEP stigma is not just about the medication—it is about reclaiming autonomy over sexual health, overcoming the legacies of colonization, and challenging the dominant narratives that continue to pathologize Indigenous bodies. Drivers of stigma, the underlying causes that determine whether a condition is stigmatized (Stangl et al., 2019), must be understood in relation to Indigenous histories and contemporary context (Biello et al., 2021; Elopre et al., 2018). Previous studies have identified potential drivers of PrEP stigma to include HIV stigma (Golub et al., 2017; Jani et al., 2021; Wood et al., 2019), stigma surrounding key populations such as people who use drugs (Biello et al., 2021), men who have sex with men (Brooks et al., 2020), discrimination (Irvin et al., 2014), and a deeply entrenched distrust of healthcare systems (Elopre et al., 2018; Mayer et al., 2020). While drivers have been primarily identified in populations of men who have sex with men (Dubov et al., 2018), and among some women (Goparaju et al., 2017), there is a gap in knowledge regarding the PrEP stigma drivers in Indigenous communities.

This study aims to explore the drivers of PrEP stigma, specifically within Indigenous communities, recognizing the need for culturally grounded interventions. Understanding these drivers will help inform strategies to dismantle stigma, enhance health equity, and empower Indigenous people to reclaim their sexual health on their own terms.

METHODS

Study Design and Setting

A cross-sectional online survey was conducted to examine PrEP knowledge, attitudes, and perceived barriers to use among Indigenous people in the United States, including the effects of stigma on PrEP use. The detailed methods, study questionnaire, participant demographics, and additional findings related to associations between sociodemographic characteristics and PrEP stigma are published separately (Roberts et al., 2025). In the current analysis, we sought to test the associations between perceived PrEP stigma and five potential drivers of PrEP stigma: 1)

² Lesbian, Gay, Bisexual, Transgender, Questioning, Intersex, Asexual, and Two-Spirit.

perceived HIV stigma, 2) perceived drug use stigma, 3) perceived sexual orientation and gender identity stigma, 4) medical mistrust, and 5) experiences of discrimination. Because the survey was not restricted to people who used PrEP, were living with HIV, identified as sexual or gender minorities, or used drugs, questions were focused on perceived stigma, rather than anticipated or experienced stigma that would be faced by members of these stigmatized groups.

Study Population and Recruitment

To be eligible for this study, individuals had to meet the following inclusion criteria: 1) self-identify as American Indian or Alaska Native (AI/AN), including, but not limited to, Indigenous, Native American, American Indian, Alaska Native, Native Hawaiian, or Pacific Islander, 2) self-report age ≥ 16 years, and 3) able to read and respond to the survey in English.

A convenience sampling method was utilized; participants were recruited through e-mail, text message, and social media platforms, all which were managed by the Northwest Portland Area Indian Health Board. Participant recruitment was conducted in three phases. During the first phase of recruitment, the online survey was distributed to members of two email listservs, both of which were selected because they reach large numbers of AI/AN individuals. These listservs included a mix of nationwide and local audiences, with subscriber counts ranging from 140 to 6,610. Among the subscribers were youths, individuals identifying as 2SLGBTQ+, health educators, and clinicians. Prior to survey distribution, project investigators shared general information regarding the survey to the listservs to increase the response rate. Then, unique links to the survey were sent to each email address associated with the listservs. In the second phase, we recruited by sending a mass message describing the survey to two SMS distribution lists and requesting interested individuals to respond with a phrase to a phone number. All respondents received a unique link to complete the online survey. In phase 3, participants were recruited through Instagram by posting about the survey and asking interested viewers to text a phrase to a specific phone number. Once again, those who responded received a unique link to complete the survey.

Individuals who received the survey via email or text messaging had the opportunity to refer other individuals by providing their email address or phone number for contact. After completion of the survey, respondents were provided a referral link to directly share to their networks. After verification and removal of duplicate referrals, a unique survey link was distributed to referrals.

Data Collection, Management, and Fraud Detection

The data were collected between January 23 through April 28, 2023. Respondents' unique survey link directed them to a survey landing page, which included a brief consent form to screen for the survey. All individuals who consented were directed to begin the self-administered screener instrument. Eligible respondents were then directed to an online consent form for the full survey. If consent was granted, they proceeded to the full survey. The screener and survey instrument were programmed in Voxco, a secure web-based data collection system. Survey completion data were screened using Google's reCAPTCHA V3 to eliminate robot survey completions ('bots'). Additionally, staff members monitored all screener and survey data files to flag fraudulent activity. Final decisions of validity of flagged responses were discussed among study team members.

Measures

The survey measured sociodemographic characteristics including age (years), race and ethnicity, gender identity, sexual orientation, geographic residence (i.e., urban, suburban, or rural; on reservation/tribal lands or not), and type of healthcare facility utilized (i.e., private, Indian Health Service, Tribal, or Urban Indian facility).

Before distribution, the following scales included in the survey underwent a thorough review to avoid duplication. Each scale was carefully assessed for content overlap, with redundant items either rephrased or eliminated. Furthermore, some items were removed or rephrased due to their lack of cultural relevance. This process ensured that the survey captured culturally appropriate perspectives while maintaining the integrity of the constructs being measured.

Perceived PrEP stigma was assessed with a 19-item scale, $\alpha = 0.90$. Due to the lack of validated perceived PrEP stigma scales, the authors adapted all items from the PrEP Stigma and Positive Attitudes scale (Mustanski et al., 2018) and 9 of 12 items from the HIV Pre-exposure Prophylaxis Stigma Scale (Siegler et al., 2020) by reframing the questions to reflect what people in the community think instead of what the respondents think about HIV and PrEP use. Perceived PrEP stigma items were administered after participants completed the PrEP knowledge section and viewed a brief informational video that defined PrEP, described who it is for and its effectiveness in preventing HIV, and noted that it does not protect against other sexually transmitted infections.

Perceived HIV stigma was assessed with 5 of 12 items from The Concern With Public Attitudes About People With HIV subscale of the HIV Stigma Scale (Berger et al., 2001) ($\alpha = 0.94$).

Perceived sexual orientation and gender identity stigma was assessed with a subset of 8 items from a tool designed to evaluate a stigma reduction training in Jamaica that was adapted from an existing scale assessing attitudes towards rights of individuals who identify as lesbian and gay (Poteat et al., 2017) ($\alpha = 0.90$).

Perceived drug use stigma was assessed with 8 of 10 items from the Stigma of Drug Users Scale (Palamar et al., 2011) ($\alpha = 0.88$).

To measure medical mistrust, 10 of 12 items were used from the Group-based Medical Mistrust Scale (GBMMS) (Thompson et al., 2004) ($\alpha = .93$). With this measure, individuals were asked about experiences with doctors and other health care providers where individuals seek health care most of the time.

For all of the above scales, the response options were on a 5-point Likert scale (“strongly disagree to strongly agree”). All scores were calculated as means (potential range 1-5) except for the perceived HIV stigma scale, for which the score was calculated as a total (range 5-25) following the authors’ instructions (Berger et al., 2001). Higher scores across the scales indicated higher experiences of stigma. Items throughout the scales were reverse coded as needed.

Experiences of discrimination was measured with the Everyday Discrimination Measure (Williams et al., 1997) ($\alpha = .93$). Respondents answered 9 items on how often they experienced a form of discrimination in their day-to-day life. These items were measured on a six-point scale of (0) never, (1) less than once a year, (2) a few times a year, (3) a few times a month, (4) at least once a week, and (5) almost every day. The responses to these five items were summed for a possible score from 0 to 45, with higher scores indicating more experiences of discrimination. Individuals who reported discrimination at least “a few times a year” answered a subsequent question of what they believe is the main reason for these experiences.

Ethics Statement

The study protocol was reviewed and approved by the Portland Area Institutional Review Board. All participants provided informed consent in English, and a waiver of parental consent was granted for minors aged 16-17 years. E-gift cards in the amount of \$100 were dispersed to respondents who completed the survey and shared their knowledge. Participants were not aware of the amount of the gift card until after the completion of the survey.

Data Analysis

The statistical analysis included all participants (n=354) who completed the study. Descriptive statistics were conducted to summarize demographic characteristics of survey respondents and scores and item response frequencies for each stigma scale. Linear regression models were utilized to estimate associations between perceived PrEP stigma and the hypothesized drivers: perceived drug use stigma, perceived HIV stigma, perceived sexuality stigma, medical mistrust, and experiences of discrimination. Multivariable models adjusted for age (as tertiles), sexual orientation, gender identity, and living on reservation or tribal lands. All analyses were conducted using Stata version 17.

RESULTS

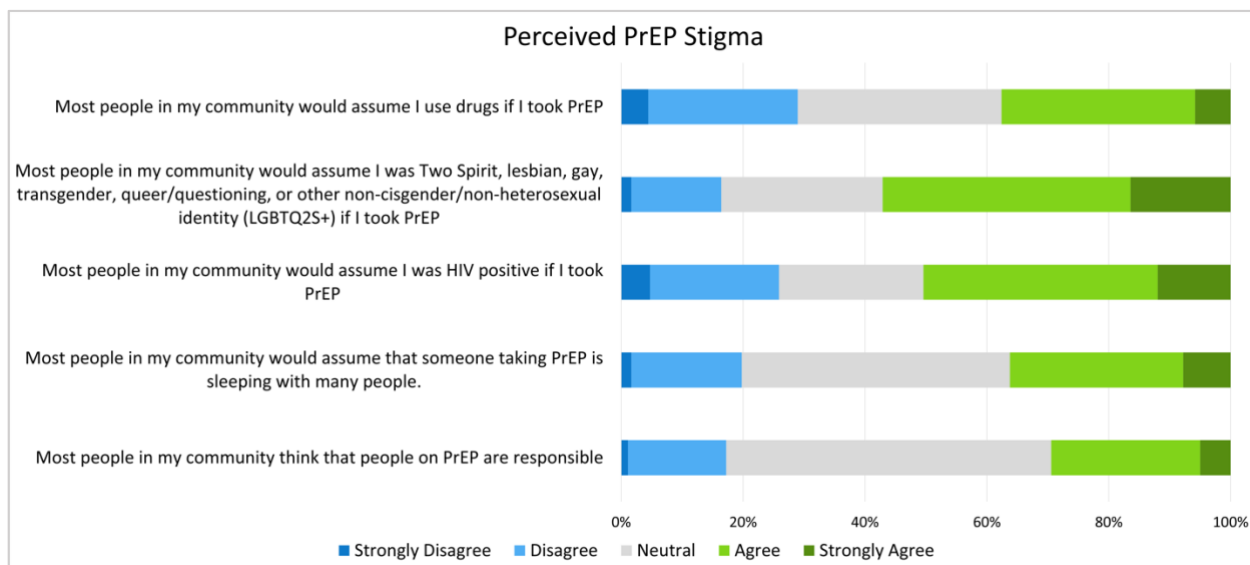
Demographic Characteristics of Study Participants

A total of 354 Indigenous-identifying participants completed the survey and were included in this analysis (median age: 41, Inter-quartile range: 30-50 years). In our sample, 61% identified as women, 18% as men, and 21% as another gender identity (including Two Spirit, Indigiqueer, transgender, and non-binary); 62% reported their sexual identity as straight and 38% as non-straight, including bisexual, gay, lesbian, queer, or pansexual. Over half of participants reported as living off reservation (69%), specifically in urban areas (68%). Of the participants living on reservation/tribal lands (31%), almost all live in rural areas (78%).

Perceived PrEP Stigma

Out of the 354 participants, 73% disagreed or strongly disagreed that their community knew the purpose of PrEP. The mean score on the Perceived PrEP Stigma scale was 3.0 out of 5 (SD 0.5), reflecting overall neutral attitudes on how stigma is perceived to be directed towards people who use PrEP by their community. The items with the highest proportion of respondents agreeing or strongly agreeing demonstrated an assumed association of PrEP use with using drugs (38%), non-cisgender/non-heterosexual identity (57%), HIV positive status (50%), or sleeping with many people (36%) (Figure 1). When asked if most people in their community would associate PrEP users “as being responsible,” 29% agreed or strongly agreed.

Figure 1. Perceived PrEP stigma



Note. Participants were asked to rate how strongly they agree with each statement about their community's attitudes and beliefs about PrEP.

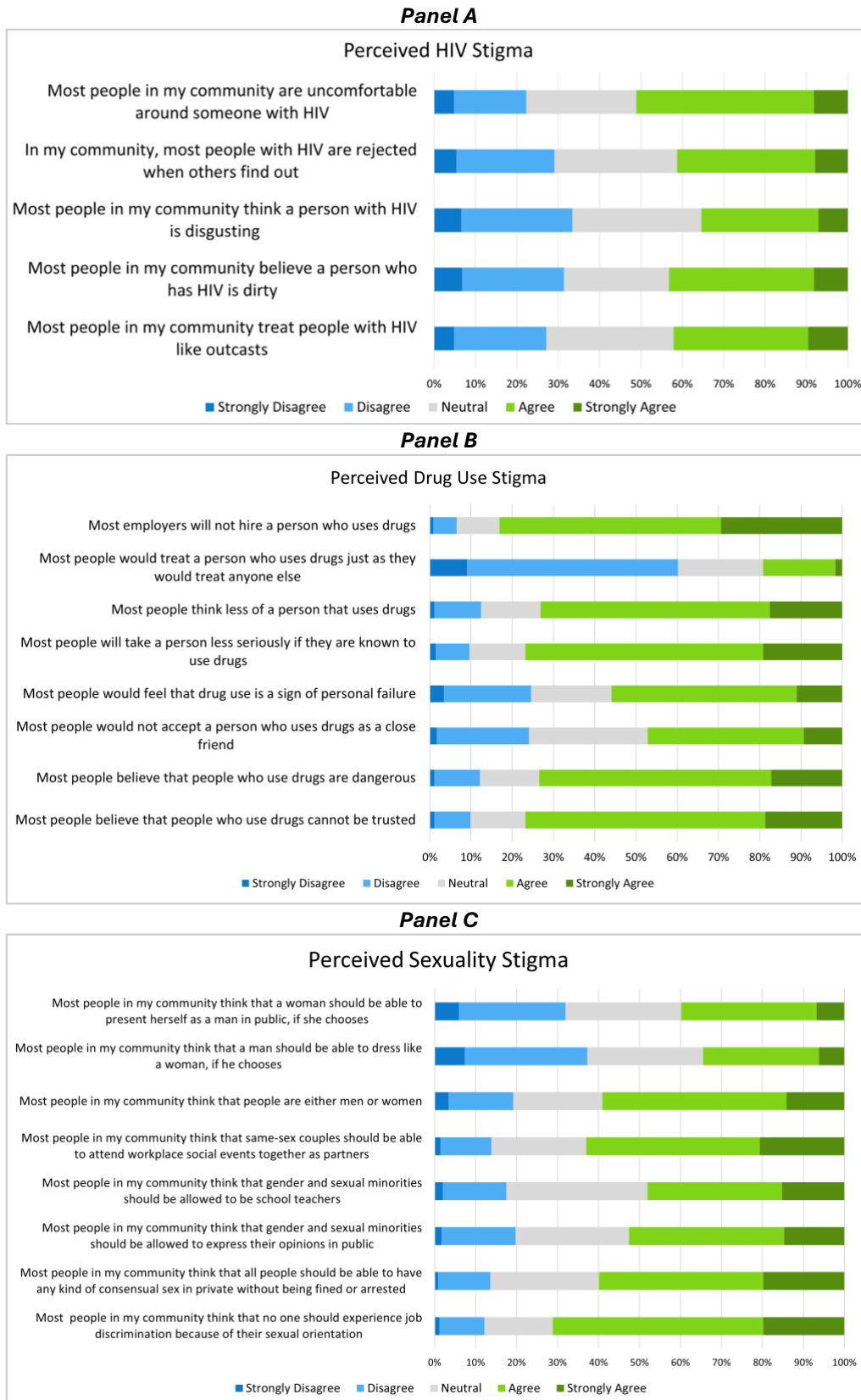
Drivers of PrEP Stigma

The mean scores for each hypothesized driver are shown in Table 2 and indicate moderate to high levels of drug use, HIV, and sexual orientation and gender identity stigma; medical mistrust; and experienced discrimination. Participants perceived high levels of HIV stigma from their community (Figure 2, Panel A). The highest proportion of respondents agreed/strongly agreed to the statement that most people in their community treat people with HIV as outcasts (51%). About 41% of respondents agreed or strongly agreed that in their respective community, most people with HIV are rejected when others find out.

On the Perceived Drug Use Stigma scale (Figure 2, Panel B), high proportions of respondents agreed or strongly agreed that most people in their community believe that people who use drugs cannot be trusted (77%), are dangerous (73%), and are less of a person due to drug use (73%).

On the Perceived Sexuality Stigma scale (Figure 2, Panel C), almost 60% of respondents agreed or strongly agreed with the statement "people are either men or women." Approximately 37% of the respondents disagreed or strongly disagreed that most people in their community think that a man should be able to dress like a woman, if he chooses.

Figure 2. Perceived HIV Stigma, Drug Use Stigma, and Sexual Orientation and Gender Identity Stigma

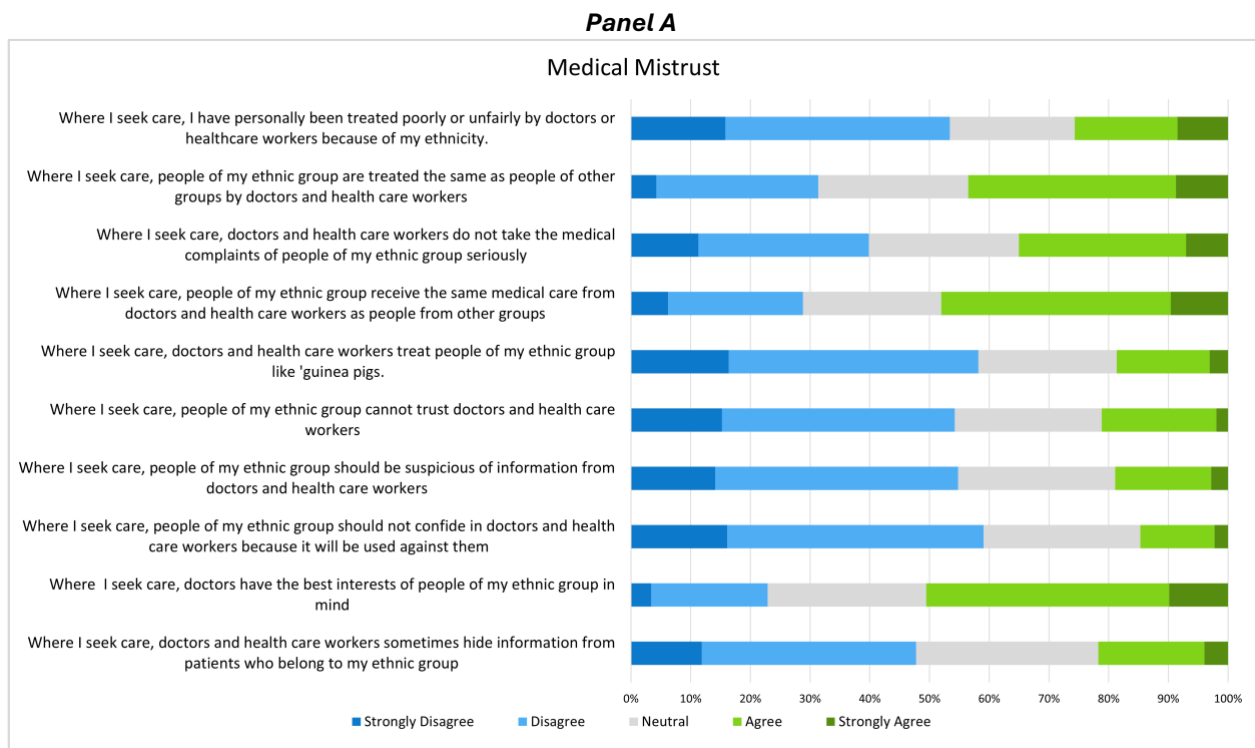


Note. For all three panels participants were asked to rate how strongly they agree with each statement regarding their community’s attitudes towards and beliefs about HIV, drug use, and sexual orientation and gender identity.

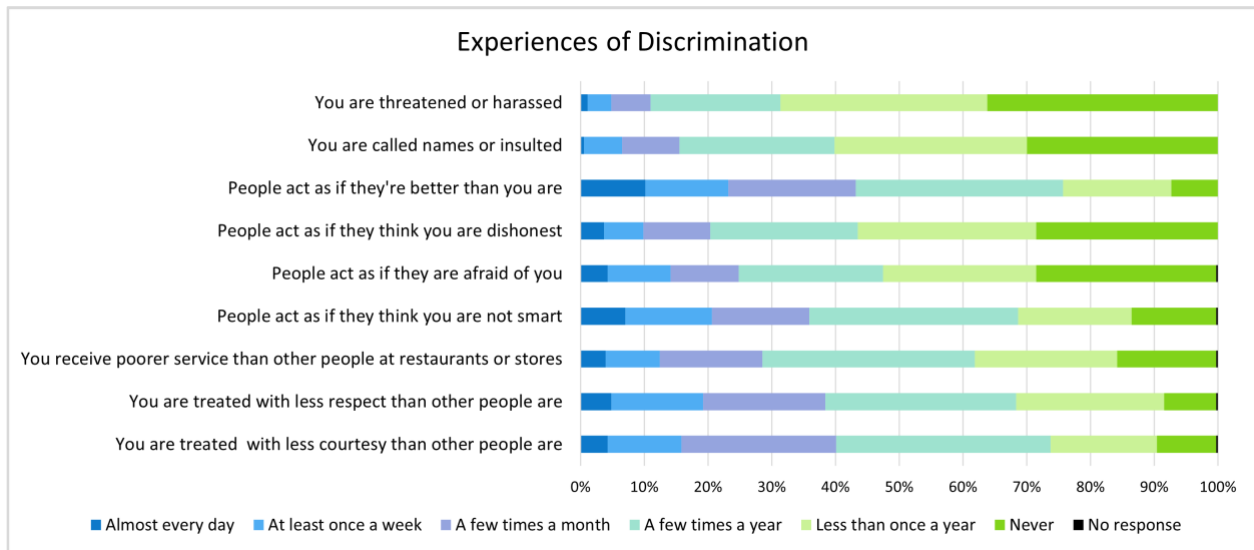
On the Medical Mistrust scale (Figure 3, Panel A), approximately 35% of respondents agreed or strongly agreed that health care workers do not take the medical complaints of people of their ethnic group seriously.

On the Experiences of Discrimination scale (Figure 3, Panel B), the frequencies of experiences for each type of discrimination varied. For example, participants’ experience of being treated with less courtesy ranged from never (9%) to those who reported it happening a few times a year (34%) to those who are experiencing it monthly (24%) or even more frequently (12% weekly, 4% almost every day). Similarly, for experiences of being treated with less respect than other people, participants responses ranged from never (8%) to happening a few times a year (30%) to monthly (19%) or even more frequently (14% weekly, 5% daily). A majority of respondents attributed their experiences of discrimination to their Indigeneity or their Ancestry or National Origins (58%), and/or gender (45%), and/or race (45%) (Table 1). Additionally, 20% of respondents identified their sexual orientation as a reason for their experiences of discrimination.

Figure 3. Medical Mistrust and Experiences of Discrimination



Panel B



Note. Participants were asked to rate how strongly they agree to the following experiences with doctors and other health care providers where they seek health care most of the time, as well as their experiences of discrimination happening to them in their day-to-day life.

Table 1.
Reasons for discrimination (N = 354)

Characteristic	N	%
Indigeneity	189	53.4
Your Ancestry or National Origins	97	27.4
Either of the above	206	58.2
Gender	158	44.6
Race	158	44.6
Shade of skin color	142	40.1
Age	97	27.4
Education or Income Level	84	23.7
Sexual Orientation	69	19.5
Religion	26	7.3
Others thinking that you use illicit drugs or prescription medication illicitly	18	5.1
HIV status	1	3.1
PrEP use	10	2.8

Associations between Perceived PrEP Stigma and Hypothesized Drivers

In the bivariate analysis (Table 2), perceived PrEP stigma was statistically significantly associated with perceived drug use stigma ($\beta = 0.28$, CI 0.22-0.35, $p < 0.001$), perceived HIV stigma ($\beta = 0.05$, CI 0.04-0.06, $p < 0.001$), and perceived sexuality stigma ($\beta = 0.29$, CI 0.23-0.35, $p < 0.001$).

There were also statistically significant associations between perceived PrEP stigma and medical mistrust ($\beta = 0.15$, CI 0.10 – 0.21, $p < 0.001$) and experiences of discrimination ($\beta = 0.007$, CI 0.001 – 0.12, $p = 0.01$). These estimates were similar after adjustment for potential confounders: age, gender identity, sexual orientation, and living on tribal lands.

Table 2.
Linear regression model of associations between perceived stigma and drivers of PrEP use stigma

	Mean (SD)	Association with perceived stigma score	
		Unadjusted β , 95% CI, p-value	Adjusted* β , 95% CI and p-value
Perceived HIV stigma score (range 5-25)	16 (4.7)	0.05 (0.04, 0.06) <0.001	0.05 (0.04, 0.06) <0.001
Perceived sexuality stigma score (range 1-5)	2.7 (0.8)	0.29 (0.23, 0.35) <0.001	0.28 (0.22, 0.34) <0.001
Perceived drug use stigma score (range 1-5)	3.7 (0.7)	0.28 (0.22, 0.35) <0.001	0.27 (0.20, 0.34) <0.001
Medical mistrust (range 1-5)	2.6 (0.8)	0.15 (0.10, 0.21) <0.001	0.14 (0.08, 0.21) <0.001
Experiences of discrimination (range 0-45)	16.6 (9.5)	0.007 (0.001, 0.12) 0.01	0.007 (0.001, 0.12) 0.02

* Adjusted for age, gender identity, sexual orientation, and living on tribal lands.

DISCUSSION

This study illuminates three key findings on drivers of perceived PrEP use stigma in Indigenous communities, grounded in cultural, historical, and social realities. First, respondents perceived that people in their communities associated PrEP use with behaviors and identities often stigmatized within their communities, including drug use, being 2SLGBTQ+, living with HIV, and having multiple sexual partners. Second, high levels of stigma tied to these behaviors, alongside experiences of discrimination and deeply rooted mistrust of the medical systems, were consistently reported. Third, the correlation between HIV, sexuality, and drug use stigma, discrimination, and medical mistrust with perceived PrEP stigma among the respondents reinforces our hypothesis that these factors may impact PrEP use within Indigenous communities.

Our findings echo previous studies that link PrEP use with stigmatized identities, such as men who have sex with men (MSM), women living with HIV, as well as other people living with HIV. Specifically, studies focused on diverse populations of MSM and women living with HIV

reported community perceptions that PrEP use indicated living with HIV, sexual orientation and gender identity status, and being sexually promiscuous (Andrade et al., 2023; Brooks et al., 2020; Calabrese et al., 2018; Eaton et al., 2017; Golub, 2018; Golub et al., 2017; Goparaju et al., 2017; Grace et al., 2018; Quinn et al., 2019). Our study adds a critical perspective by identifying similar stigma within a general Indigenous population, while also introducing new data on the association of PrEP use and drug use. This association may stem from early public health messaging that framed PrEP as primarily for “high-risk groups” such as people who inject drugs, sex workers, and men who have sex with men (Golub, 2018; Özdener-Poyraz et al., 2020). This initial messaging for PrEP resulted in assumptions that PrEP users must belong to one of those groups. Such messaging has been perceived to create a lasting impact, which fosters assumptions that reinforce the stigma around PrEP use. In Indigenous communities, where historical and present-day trauma related to healthcare remains a potent reality, such assumptions can discourage providers from initiating conversations about sexual health, substance use, or PrEP eligibility. When providers do not proactively ask or offer, patients who could benefit from PrEP may never be identified, further limiting access and perpetuating existing health disparities.

Consistent with previous studies of racial and gender diverse populations, the respondents of our study perceive high levels of stigma around HIV, sexual orientation, gender identity, and drug use stigma from members of their community (Hatala et al., 2018; Jongbloed et al., 2019; Lydon-Hassen et al., 2022; Padilla et al., 2022; Prescott et al., 2024). The experiences of stigma have profound implications for the health and wellbeing of individuals. The social isolation and marginalization, mental health strain, and barriers to care that stigma produces exacerbate systemic inequities and further entrench health disparities within Indigenous populations (Díaz et al., 2001; Hatzenbuehler, 2009; Pachankis, 2007; Stangl et al., 2019). Furthermore, stigma can exacerbate systemic inequities and health disparities by reducing healthcare utilization such as preventative care and treatment (Dubov et al., 2018; Hatzenbuehler et al., 2013; Pachankis, 2007; Stangl et al., 2019). For Indigenous people, these stigmas intersect with historical trauma and ongoing marginalization, contributing to the stark disparities in HIV prevention and care seen today (Armenta et al., 2021; Burks et al., 2011; Lydon-Hassen et al., 2022; McCall et al., 2009).

The pervasive medical mistrust reported by respondents is another crucial factor for understanding PrEP stigma within Indigenous communities. Distrust in healthcare systems is rooted in generations of medical exploitation and mistreatment. Historical examples, such as non-consensual medical practices and forced sterilization, continue to shape healthcare interactions

today (Armenta et al., 2021; Guadagnolo et al., 2009; Roberson, 1994). This mistrust, coupled with discrimination in healthcare settings, has profound implications on whether individuals seek to continue to engage with medical services. For example, individuals who mistrust medical providers and the health care system may delay seeking or utilizing healthcare services and adhering to treatment. Discrimination in healthcare settings further magnifies distrust and negatively impacts treatment-seeking behavior. Our findings demonstrate that discrimination and mistrust are associated with increased PrEP stigma, which in turn hinders PrEP uptake and adherence. These results align with previous research that have linked these factors to poor healthcare outcomes in AI/AN populations (Burks et al., 2011; Lyons et al., 2015).

Our findings underscore that PrEP stigma in Indigenous communities is closely tied to broader stigmas around HIV, drug use, Two-Spirit and LGBTQ+ identities, medical mistrust, and ongoing experiences of discrimination. These findings contribute to the growing body of literature on stigma as a barrier to PrEP and HIV care in marginalized populations (Cahill et al., 2017; Grace et al., 2018; McCall et al., 2009; Mustanski et al., 2024) and offer a novel focus on Indigenous communities, where these challenges are often intertwined with the legacies of colonization and systemic oppression.

The results of this study call for culturally tailored interventions that address the unique drivers of PrEP stigma in Indigenous communities. Educational campaigns that emphasize PrEP as a tool for wellness rather than solely as an HIV risk-reduction strategy could help shift harmful narratives and reduce stigma (Rosen et al., 2023). These campaigns must be rooted in Indigenous values, traditions, and history and delivered through trusted community members who can offer culturally responsive, community-led approaches to health promotion (Burks et al., 2011). Utilizing community health workers could provide for a more effective, sustainable, and tribal-led approach to stigma reduction in the Indigenous communities. In a study of gay, bisexual, and two-spirit AI/AN men, the participants reported that they believe HIV prevention and intervention efforts would be more effective if American Indian outreach workers provided the peer and community education (Burks et al., 2011). Additionally, training healthcare providers to be culturally humble and responsive to the specific needs of Indigenous individuals is crucial in rebuilding trust and ensuring equitable access to PrEP and other healthcare services (Hoover et al., 2023).

Finally, adopting a harm reduction approach that bridges HIV prevention with substance use support can be an effective way to reduce stigma associated with both PrEP use and drug use.

Harm reduction, when led by Indigenous communities, can offer a person-centered and culturally grounded approach to health promotion, risk reduction, and healing. Tribal communities that already implement harm reduction strategies are uniquely positioned to transform perceptions around drug use and PrEP, ultimately working towards the reduction of both HIV and substance use-related stigma.

This study has several key limitations. First, our study utilized a convenience sample approach which resulted in our study population not being fully representative of Indigenous People in the United States. Specifically, our study population included a limited number of rural and reservation-based participants, which makes it difficult to draw meaningful conclusions about stigma within these populations. Although not necessarily underrepresented relative to national demographics (U.S. Department of Health and Human Services Office of Minority Health, 2025), the small sample size from non-urban and reservation-based communities may limit our understanding of how stigma varies across demographics such as gender, age, and geographic region. These communities may experience different social dynamics, cultural contexts, and healthcare challenges that shape perceptions of PrEP use. Within our sample, there was a disproportionate representation of women and older adults with comparatively fewer responses from men and younger adults. Nonetheless, our methodology enabled us to efficiently engage a broad spectrum of Indigenous individuals ensuring diversity across geographic regions, sexual orientations, and gender identities. Second, we were not able to validate the PrEP stigma scales utilized with Indigenous respondents. There is a risk that some of the items lack relevance to the focus of our study or were misunderstood by the participants. Third, with our cross-sectional study design, we were not able to distinguish causation in the association between the drivers of PrEP stigma and perceived PrEP stigma. Finally, there may be other drivers of stigma that we did not assess.

CONCLUSION

This study highlights the complex drivers of PrEP stigma in Indigenous communities, emphasizing the intersection of HIV, drug use, 2SLGBTQ+ stigma, medical mistrust, and historical trauma. The association of PrEP use with stigmatized identities and behaviors, compounded by discrimination and mistrust in healthcare, creates barriers to PrEP uptake and adherence. Culturally grounded interventions are needed to address these drivers of stigma,

emphasizing PrEP as a tool for wellness. Community-led approaches, such as the use of trusted health workers and harm reduction strategies, can support Indigenous people in reclaiming their health and reducing disparities in HIV prevention.

ACKNOWLEDGEMENTS

The authors acknowledge the American Indian and Alaska Native people who participated in this survey and thank them for their valuable contributions. We also thank Jane Manthei, David Stephens, and Roger Peterson at the NPAIHB for their support in participant recruitment.

FUNDING INFORMATION

This project was funded by the Indian Health Service (IHS) with funds from the Minority HIV/AIDS Fund via IHS. The funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript. The opinions expressed in this paper are those of the authors and do not necessarily reflect the views of IHS.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR INFORMATION

Monica M. Desjardins, MPH (Diné), is an Epidemiologist at the Research Triangle Institute (RTI) International in Research Triangle Park, NC, and a doctoral student in the Department of Mental Health at the Johns Hopkins Bloomberg School of Public Health in Baltimore, MD.

Jessica Leston, MPH (Tsimshian), is an owner/partner at The Raven Collective in Greyslake, IL.

Erica N Browne, MS, is a Research Statistician at the Research Triangle Institute (RTI) International in Research Triangle Park, NC.

Sarah M. Hatcher, PhD, was a Research Epidemiologist at the Research Triangle Institute (RTI) International in Durham, NC. She is currently an Epidemiology Supervisor at the North Carolina Department of Health and Human Services, Division of Public Health in Durham, NC.

Brigg Reilley, MPH, is an Epidemiologist at The Raven Collective in Greyslake, IL.

Ashley Hoover, MPH, is an Epidemiologist at The Raven Collective in Greyslake, IL.

Andrew Freeman, BA, is a Public Health Analyst at the Research Triangle Institute (RTI) International in Research Triangle Park, NC.

Matthew Bensen, MA, is a Systems Analysis and Programming Manager at the Research Triangle Institute (RTI) International in Research Triangle Park, NC.

Bob Henne, BS, is a Systems Analysis and Programming Manager at the Research Triangle Institute (RTI) International in Research Triangle Park, NC.

Sarah T Roberts, PhD, is a Senior Research Epidemiologist at the Research Triangle Institute (RTI) International in Research Triangle Park, NC.

REFERENCES

Andrade, E. A., Stoukides, G., Santoro, A. F., Karasz, A., Arnsten, J., & Patel, V. V. (2023). Individual and health system factors for uptake of pre-exposure prophylaxis among young Black and Latino gay men. *Journal of General Internal Medicine*, 38(12), 2768–2774. <https://doi.org/10.1007/s11606-023-08274-5>

Armenta, R. F., Kellogg, D., Montoya, J. L., Romero, R., Armao, S., Calac, D., & Gaines, T. L. (2021). “There is a lot of practice in not thinking about that”: Structural, interpersonal, and individual-level barriers to HIV/STI prevention among reservation-based American Indians. *International Journal of Environmental Research and Public Health*, 18(7). Scopus. <https://doi.org/10.3390/ijerph18073566>

Baeten, J. M., Donnell, D., Ndase, P., Mugo, N. R., Campbell, J. D., Wangisi, J., Tappero, J. W., Bukusi, E. A., Cohen, C. R., Katabira, E., Ronald, A., Tumwesigye, E., Were, E., Fife, K. H., Kiarie, J., Farquhar, C., John-Stewart, G., Kakia, A., Odoyo, J., ... Celum, C. (2012). Antiretroviral prophylaxis for HIV-1 prevention among heterosexual men and women. *The New England Journal of Medicine*, 367(5), 399–410. <https://doi.org/10.1056/NEJMoal108524>

Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*, 24(6), 518–529. <https://doi.org/10.1002/nur.10011>

- Biello, K. B., Mimiaga, M. J., Valente, P. K., Saxena, N., & Bazzi, A. R. (2021). The past, present, and future of PrEP implementation among people who use drugs. *Current HIV/AIDS Reports*, 18(4), 328–338. <https://doi.org/10.1007/s11904-021-00556-z>
- Brooks, R. A., Nieto, O., Landrian, A., Fehrenbacher, A., & Cabral, A. (2020). Experiences of Pre-Exposure Prophylaxis (PrEP)-related stigma among Black MSM PrEP users in Los Angeles. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, 97(5), 679–691. <https://doi.org/10.1007/s11524-019-00371-3>
- Burks, D. J., Robbins, R., & Durtschi, J. P. (2011). American Indian gay, bisexual and two-spirit men: A rapid assessment of HIV/AIDS risk factors, barriers to prevention and culturally-sensitive intervention. *Culture, Health & Sexuality*, 13(3), 283–298. <https://doi.org/10.1080/13691058.2010.525666>
- Cahill, S., Taylor, S. W., Elsesser, S. A., Mena, L., Hickson, D., & Mayer, K. H. (2017). Stigma, medical mistrust, and perceived racism may affect PrEP awareness and uptake in black compared to white gay and bisexual men in Jackson, Mississippi and Boston, Massachusetts. *AIDS Care*, 29(11), 1351–1358. <https://doi.org/10.1080/09540121.2017.1300633>
- Calabrese, S. K., Dovidio, J. F., Tekeste, M., Taggart, T., Galvao, R. W., Safon, C. B., Willie, T. C., Caldwell, A., Kaplan, C., & Kershaw, T. S. (2018). HIV Pre-Exposure Prophylaxis stigma as a multidimensional barrier to uptake among women who attend Planned Parenthood. *Journal of Acquired Immune Deficiency Syndromes (1999)*, 79(1), 46–53. <https://doi.org/10.1097/QAI.0000000000001762>
- Centers for Disease and Control and Prevention. (2024). *Diagnoses, Deaths, and Prevalence of HIV in the United States and 6 Territories and Freely Associated States, 2022* (HIV Surveillance Report, 2022 No. 35). <https://stacks.cdc.gov/view/cdc/156509>
- Díaz, R. M., Ayala, G., Bein, E., Henne, J., & Marin, B. V. (2001). The impact of homophobia, poverty, and racism on the mental health of gay and bisexual Latino men: Findings from 3 US cities. *American Journal of Public Health*, 91(6), 927–932. <https://doi.org/10.2105/ajph.91.6.927>

- Dubov, A., Galbo, P., Altice, F. L., & Fraenkel, L. (2018). Stigma and shame experiences by msm who take PrEP for HIV prevention: A qualitative study. *American Journal of Men's Health, 12*(6), 1843–1854. <https://doi.org/10.1177/1557988318797437>
- Eaton, L. A., Kalichman, S. C., Price, D., Finneran, S., Allen, A., & Maksut, J. (2017). Stigma and conspiracy beliefs related to Pre-exposure Prophylaxis (PrEP) and interest in using PrEP among Black and White men and transgender women who have sex with men. *AIDS and Behavior, 21*(5), 1236–1246. <https://doi.org/10.1007/s10461-017-1690-0>
- Elopre, L., McDavid, C., Brown, A., Shurbaji, S., Mugavero, M. J., & Turan, J. M. (2018). Perceptions of HIV Pre-Exposure Prophylaxis among young, Black men who have sex with men. *AIDS Patient Care and STDs, 32*(12), 511–518. <https://doi.org/10.1089/apc.2018.0121>
- Golub, S. A. (2018). PrEP Stigma: Implicit and explicit drivers of disparity. *Current HIV/AIDS Reports, 15*(2), 190–197. <https://doi.org/10.1007/s11904-018-0385-0>
- Golub, S. A., Gamarel, K. E., & Surace, A. (2017). Demographic differences in PrEP-related stereotypes: Implications for implementation. *AIDS and Behavior, 21*(5), 1229–1235. <https://doi.org/10.1007/s10461-015-1129-4>
- Goparaju, L., Praschan, N. C., Warren-Jeanpiere, L., Experton, L. S., Young, M. A., & Kassaye, S. (2017). Stigma, partners, providers and costs: Potential barriers to PrEP uptake among US women. *Journal of AIDS & Clinical Research, 8*(9), 730. <https://doi.org/10.4172/2155-6113.1000730>
- Grace, D., Jollimore, J., MacPherson, P., Strang, M. J. P., & Tan, D. H. S. (2018). The Pre-Exposure Prophylaxis-stigma paradox: Learning from Canada's first wave of PrEP users. *AIDS Patient Care and STDs, 32*(1), 24–30. <https://doi.org/10.1089/apc.2017.0153>
- Guadagnolo, B. A., Cina, K., Helbig, P., Molloy, K., Reiner, M., Cook, E. F., & Petereit, D. G. (2009). Medical mistrust and less satisfaction with health care among Native Americans presenting for cancer treatment. *Journal of Health Care for the Poor and Underserved, 20*(1), 210–226. <https://doi.org/10.1353/hpu.0.0108>

- Hatala, A. R., Bird-Naytowhow, K., Pearl, T., Peterson, J., del Canto, S., Rooke, E., Calvez, S., Meili, R., Schwandt, M., Mercredi, J., & Tait, P. (2018). Being and becoming a helper: Illness disclosure and identity transformations among Indigenous people living with HIV or AIDS in Saskatoon, Saskatchewan. *Qualitative Health Research*, 28(7), 1099–1111. <https://doi.org/10.1177/1049732318764394>
- Hatzenbuehler, M. L. (2009). How does sexual minority stigma “get under the skin”? A psychological mediation framework. *Psychological Bulletin*, 135(5), 707–730. <https://doi.org/10.1037/a0016441>
- Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*, 103(5), 813–821. <https://doi.org/10.2105/AJPH.2012.301069>
- Hoover, A., Jeffries, I., Thomas, M., & Leston, J. (2023). Health care access and lived experience of American Indian/Alaska Native Two Spirit and LGBTQ+ participants in the Pride and Connectedness Survey, 2020. *Public Health Reports*, 138(2_suppl), 48S-55S. <https://doi.org/10.1177/00333549231151650>
- Irvin, R., Wilton, L., Scott, H., Beauchamp, G., Wang, L., Betancourt, J., Lubensky, M., Wallace, J., & Buchbinder, S. (2014). A study of perceived racial discrimination in Black men who have sex with men (MSM) and its association with healthcare utilization and HIV testing. *AIDS and Behavior*, 18(7), 1272–1278. <https://doi.org/10.1007/s10461-014-0734-y>
- Jani, N., Mathur, S., Kahabuka, C., Makyao, N., & Pilgrim, N. (2021). Relationship dynamics and anticipated stigma: Key considerations for PrEP use among Tanzanian adolescent girls and young women and male partners. *PloS One*, 16(2), e0246717. <https://doi.org/10.1371/journal.pone.0246717>
- Jongbloed, K., Pooyak, S., Sharma, R., Mackie, J., Pearce, M. E., Laliberte, N., Demerais, L., Lester, R. T., Schechter, M. T., Loppie, C., Spittal, P. M., & Cedar Project Partnership. (2019). Experiences of the HIV cascade of care among Indigenous Peoples: A systematic review. *AIDS and Behavior*, 23(4), 984–1003. <https://doi.org/10.1007/s10461-018-2372-2>

- Leston, J., Wenger, H., Reilley, B., Rushing, S. C., Rink, E., Warren, H., Howe, J., Bloomquist, P., Tah, T., Jeffries, I., Iralu, J., Thorpe, P., Apostolou, A., & Taylor, M. M. (2022). Creating a path forward: Understanding the context of sexual health and sexually transmitted infections in American Indian/Alaska Native populations – A review. *Sexual Health, 19*(4), 286. <https://doi.org/10.1071/SH22040>
- Lydon-Hassen, K., Jonah, L., Mayotte, L., Hrabowy, A., Graham, B., Missens, B., Nelson, A., Andkhoie, M., Nahachewsky, D., Yalamanchili, D. T., Gupta, S., Ndubuka, N., Khan, I., Yacoub, W., Bryson, M., & Paquette, D. (2022). Summary findings from Tracks surveys implemented by First Nations in Saskatchewan and Alberta, Canada, 2018–2020. *Canada Communicable Disease Report, 48*(4), 146–156. <https://doi.org/10.14745/ccdr.v48i04a05>
- Lyons, T., Shannon, K., Pierre, L., Small, W., Krüsi, A., & Kerr, T. (2015). A qualitative study of transgender individuals' experiences in residential addiction treatment settings: Stigma and inclusivity. *Substance Abuse Treatment, Prevention, and Policy, 10*(1), 17. <https://doi.org/10.1186/s13011-015-0015-4>
- Mayer, K. H., Agwu, A., & Malebranche, D. (2020). Barriers to the wider use of pre-exposure prophylaxis in the United States: A narrative review. *Advances in Therapy, 37*(5), 1778–1811. <https://doi.org/10.1007/s12325-020-01295-0>
- McCall, J., Browne, A. J., & Reimer-Kirkham, S. (2009). Struggling to survive: The difficult reality of Aboriginal women living with HIV/AIDS. *Qualitative Health Research, 19*(12), 1769–1782. <https://doi.org/10.1177/1049732309353907>
- Mustanski, B., Queiroz, A., Merle, J. L., Zamantakis, A., Zapata, J. P., Li, D. H., Benbow, N., Pyra, M., & Smith, J. D. (2024). A systematic review of implementation research on determinants and strategies of effective HIV Interventions for men who have sex with men in the United States. *Annual Review of Psychology, 75*(Volume 75, 2024), 55–85. <https://doi.org/10.1146/annurev-psych-032620-035725>
- Mustanski, B., Ryan, D. T., Hayford, C., Phillips, G., Newcomb, M. E., & Smith, J. D. (2018). Geographic and individual associations with PrEP stigma: Results from the RADAR cohort of diverse young men who have sex with men and transgender women. *AIDS and Behavior, 22*(9), 3044–3056. <https://doi.org/10.1007/s10461-018-2159-5>

- Özdener-Poyraz, A. E., Slugocki, M., Kalabalik-Hoganson, J., & Han, J. (2020). Pre-Exposure Prophylaxis (PrEP) in the prevention of HIV: Strategies, target populations and upcoming treatments. *HIV/AIDS (Auckland, N.Z.)*, *12*, 283–293. <https://doi.org/10.2147/HIV.S216024>
- Pachankis, J. E. (2007). The psychological implications of concealing a stigma: A cognitive-affective-behavioral model. *Psychological Bulletin*, *133*(2), 328–345. <https://doi.org/10.1037/0033-2909.133.2.328>
- Padilla, M., Patel, D., Beer, L., Tie, Y., Nair, P., Salabarría-Peña, Y., Henny, K. D., Thomas, D., & Dasgupta, S. (2022). HIV stigma and health care discrimination experienced by Hispanic or Latino persons with HIV — United States, 2018–2020. *Morbidity and Mortality Weekly Report*, *71*(41), 1293–1300. <https://doi.org/10.15585/mmwr.mm7141a1>
- Palamar, J. J., Kiang, M. V., & Halkitis, P. N. (2011). Development and psychometric evaluation of scales that assess stigma associated with illicit drug users. *Substance Use & Misuse*, *46*(12), 1457–1467. <https://doi.org/10.3109/10826084.2011.596606>
- Poteat, T., Park, C., Solares, D., Williams, J. K., Wolf, R. C., Metheny, N., Vazzano, A., Dent, J., Gibbs, A., Nonyane, B. A. S., & Toiv, N. (2017). Changing hearts and minds: Results from a multi-country gender and sexual diversity training. *PLOS ONE*, *12*(9), e0184484. <https://doi.org/10.1371/journal.pone.0184484>
- Prescott, M. R., Montoya, J. L., Perry, C., Teran, R., Armenta, R., & Gaines, T. L. (2024). Community-identified implementation strategies for promoting the adoption of HIV self-testing in a Southern California American Indian community: A rapid qualitative analysis. *AIDS and Behavior*, *28*(6), 2101–2112. <https://doi.org/10.1007/s10461-024-04309-y>
- Quinn, K., Bowleg, L., & Dickson-Gomez, J. (2019). “The fear of being Black plus the fear of being gay”: The effects of intersectional stigma on PrEP use among young Black gay, bisexual, and other men who have sex with men. *Social Science & Medicine (1982)*, *232*, 86–93. <https://doi.org/10.1016/j.socscimed.2019.04.042>
- Roberson, N. L. (1994). Clinical trial participation. Viewpoints from racial/ethnic groups. *Cancer*, *74*(9 Suppl), 2687–2691. [https://doi.org/10.1002/1097-0142\(19941101\)74:9+%3C2687::aid-cncr2820741817%3E3.0.co;2-b](https://doi.org/10.1002/1097-0142(19941101)74:9+%3C2687::aid-cncr2820741817%3E3.0.co;2-b)

- Roberts, S. T., Hatcher, S. M., Browne, E. N., Reilley, B., Bensen, M., Freeman, A., Henne, B., Hoover, A., Desjardins, M. M., & Leston, J. (2025). PrEP knowledge, attitudes, and perceived barriers to access among American Indian/Alaska Native people in the US: Results from an online survey. *PLOS One*, 20(4), e0321422. <https://doi.org/10.1371/journal.pone.0321422>
- Rosen, J. G., Zhang, L., Pelaez, D., Park, J. N., & Glick, J. L. (2023). A capacity-strengthening intervention to support HIV Pre-exposure Prophylaxis (PrEP) awareness-building and promotion by frontline harm reduction workers in Baltimore, Maryland: A Mixed Methods Evaluation. *AIDS and Behavior*, 27(7), 2440–2453. <https://doi.org/10.1007/s10461-022-03971-4>
- Siegler, A. J., Wiatrek, S., Mouhanna, F., Amico, K. R., Dominguez, K., Jones, J., Patel, R. R., Mena, L. A., & Mayer, K. H. (2020). Validation of the HIV Pre-exposure Prophylaxis Stigma Scale: Performance of likert and semantic differential scale versions. *AIDS and Behavior*, 24(9), 2637–2649. <https://doi.org/10.1007/s10461-020-02820-6>
- Stangl, A. L., Earnshaw, V. A., Logie, C. H., van Brakel, W., C. Simbayi, L., Barré, I., & Dovidio, J. F. (2019). The Health Stigma and Discrimination Framework: A global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, 17, 31. <https://doi.org/10.1186/s12916-019-1271-3>
- Thompson, H. S., Valdimarsdottir, H. B., Winkel, G., Jandorf, L., & Redd, W. (2004). The Group-Based Medical Mistrust Scale: Psychometric properties and association with breast cancer screening. *Preventive Medicine*, 38(2), 209–218. <https://doi.org/10.1016/j.yjmed.2003.09.041>
- U.S. Department of Health and Human Services Office of Minority Health. (2025, August 4). *American Indian/Alaska Native Health*. American Indian/Alaska Native Health. <https://minorityhealth.hhs.gov/american-indianalaska-native-health>
- Walters, K. L., Beltran, R., Evans-Campbell, T., & Simoni, J. M. (2011). Keeping our hearts from touching the ground: HIV/AIDS in American Indian and Alaska Native women. *Women's Health Issues*, 21(6 Suppl), S261–S265. <https://doi.org/10.1016/j.whi.2011.08.005>

- Whitfield, T. H. F., Parsons, J. T., & Rendina, H. J. (2020). Rates of pre-exposure prophylaxis use and discontinuation among a large US national sample of sexual minority men and adolescents. *Archives of Sexual Behavior*, 49(1), 103–112. <https://doi.org/10.1007/s10508-019-01602-z>
- Williams, D. R., Yan Yu, null, Jackson, J. S., & Anderson, N. B. (1997). Racial differences in physical and mental health: Socio-economic status, stress and discrimination. *Journal of Health Psychology*, 2(3), 335–351. <https://doi.org/10.1177/135910539700200305>
- Wood, S., Gross, R., Shea, J. A., Bauermeister, J. A., Franklin, J., Petsis, D., Swyrn, M., Lalley-Chareczko, L., Koenig, H. C., & Dowshen, N. (2019). Barriers and facilitators of PrEP adherence for young men and transgender women of color. *AIDS and Behavior*, 23(10), 2719–2729. <https://doi.org/10.1007/s10461-019-02502-y>

Engaging Urban American Indian/Alaska Native Emerging Adults in a Nationwide Substance Use Intervention Randomized Controlled Trial: A Story of Recruitment during the COVID-19 Pandemic

Daniel L. Dickerson, DO, MPH (Inupiaq), Mel Borstad, MA, Ninna Gudgell, BA, Keisha McDonald, BS, Jennifer Parker, BA, Paige Smith, CPS, CADC-1 (Paiute, Modoc-Enrolled Klamath Tribes), Pierrce Holmes, MA, Michael J. Woodward, Carrie L. Johnson, PhD (Wahpeton Dakota), and Elizabeth J. D'Amico, PhD

Abstract: *The majority of American Indian and Alaska Native (AI/AN) peoples reside in urban areas and experience significant health disparities relating to substance use. Nonetheless, very few randomized controlled trials (RCTs) have been conducted analyzing new substance use interventions for these populations, due, in part, to challenges with recruitment. This paper highlights recruitment strategies we employed from 2021-2023 in a study, Traditions, and Connections for Urban Native Americans (TACUNA), which analyzed the benefits of a new substance use intervention for urban AI/AN emerging adults (age 18 to 25). We navigated the COVID-19 pandemic by creating virtual platforms for the interventions used in our RCT and for our recruitment strategy. By utilizing algorithms identifying the interests of our recruitment audience and effective ad combinations on Facebook and Instagram, we were able to recruit 541 participants from 37 states. This study helps to identify recruitment strategies that may help to decrease health inequities as it relates to substance use research conducted among urban AI/AN peoples.*

INTRODUCTION

Alcohol and drug (AOD) use disproportionately affects American Indian and Alaska Native (AI/AN) peoples and has disproportionately affected these populations since alcohol was introduced (Frost, 1996). From between 1999-2019 to between 2019-2021, opioid overdose rates increased among AI/AN peoples from 0.36 per 100,000 to 6.5 per 100,000 (Bauer et al., 2024), and in 2019, the alcohol-involved death rate among AI/AN people was five times higher than that in the general population (Planalp et al., 2021). Also, compared to other races and ethnicities, AI/AN peoples report higher rates of cannabis use (Center for Behavioral Health Statistics and Quality, 2024). However, research analyzing the potential benefits of new interventions to help to decrease the effects of opioid, alcohol, and cannabis use among these populations is very limited (D'Amico et al., 2020; Dickerson et al., 2020).

More than 87% of AI/AN peoples now reside outside of reservations and tribal lands (U.S. Census, 2021). This move to urban areas began with the Relocation Act of 1954 (Burt, 1986.), which resulted in coerced and forced relocation of AI/AN peoples to various urban centers throughout the United States and has continued as others search for new economic opportunities outside of reservations and tribal lands (Weaver, 2012). Some of the consequences of their movement to urban areas include diminished sense of community, fewer opportunities to engage in AI/AN traditional practices, and barriers to accessing culturally relevant health-promoting treatment and prevention programs (Brown et al., 2021; Dickerson et al., 2021a).

Health inequities in substance use experienced by urban AI/AN peoples are perpetuated by the shortage of recruitment strategies to successfully conduct studies analyzing the potential benefits of new and promising interventions that address substance use (Brockie et al., 2022; Soto et al., 2022). There are many barriers, including logistical, ethical, and socioeconomic to conducting research among AI/AN people (Mello & Wolf, 2010; Blue Bird Jernigan et al., 2020; Oberly & Macedo, 2004). Within urban areas, despite better access to public transportation, transportation costs can create challenges to engage in research programs (Dickerson et al., 2021c). Also, AI/AN peoples residing in urban areas may be more dispersed and underrecognized, which may create challenges to engaging these populations in research (Yuan et al., 2014; UIHC, 2007). Furthermore, past unethical research conducted among these populations has created a reluctance to participate in research (James et al., 2018; Wolf, 1989). Examples of past unethical research

include the use of “helicopter research,” a phenomenon whereby researchers engage AI/AN communities to conduct research but do not return to implement potentially effective programs (Petereit et al., 2011), and inappropriate reporting of findings leading to further stigmatization of substance use (Skewes et al., 2020).

Past research has often neglected to follow the principles of community-based participatory research (CBPR) which emphasizes engaging community members and Tribal Elders in every aspect of the research process, including gathering their input in recruitment, research design, interpretation, and report of results and issues relating to data sharing (Rink et al., 2020). Furthermore, there is a significant shortage of AI/AN researchers. For example, the lead author of this article is one of the few AI/AN addiction psychiatrists, to our knowledge.

Conducting randomized controlled trials (RCTs) among AI/AN peoples requires a community-engaged and collaborative approach that garners trust and partnership with AI/AN communities (Crump et al., 2020). This is especially true as it relates to substance use intervention research due to the disproportionate impact of substance use in these populations and stigma-related issues that may raise discomfort and reluctance (Hirschak et al., 2023). Strategies that address barriers to recruitment in a culturally sensitive and responsive manner can help increase successful research partnerships, thus mitigating the negative impact of historical trauma and health disparities experienced by these populations (Brave Heart & DeBruyn, 1987). To date, there are few studies and recruitment approaches that attempt to reach urban AI/AN emerging adults (age 18 to 25) nationwide, which limits critical information that can enhance our understanding of these populations and inform the development of culturally grounded substance use prevention and treatment interventions.

The COVID-19 pandemic created unprecedented challenges for researchers due to restrictions on in-person activities, leading to a need for change in the development and analysis of new health-promoting interventions. Among AI/AN people, alternate research designs that could foster engagement and capitalize on the resiliency of these populations were especially needed. In a recent special edition of this journal published in 2022, nine articles focused on a variety of topics and health-promoting interventions, highlighting their unique approaches for making necessary adaptations to their research procedures, including creating virtual-based intervention designs and recruitment procedures (Hunter et al., 2022; Kelley et al., 2022; Maudrie et al., 2022; Patel et al., 2022; Rink et al., 2022; Sinclair et al., 2022; Steinburg et al., 2022; Wells et al., 2022; Sahota et al., 2022). Four of these studies were conducted among youth and young adults (Patel et al., 2022; Steinburg et al., 2022; Wells et al., 2022; Rink et al., 2022), and two were

conducted among the general adult population (Sahota et al., 2022; Sinclair et al., 2022). However, none of the studies were conducted solely among AI/AN peoples residing outside of reservations/villages/rancherias, and none of them focused on substance use.

This paper adds to the literature by describing our recruitment strategy over a three-year period that was used to enroll urban AI/AN emerging adults into an RCT of the TACUNA (Traditions and Connections for Urban Native Americans) substance use intervention in response to challenges caused by the COVID-19 pandemic. During this period, we used innovative approaches that capitalized on the resiliency and inherent strengths of AI/AN people to recruit AI/AN emerging adults residing in urban areas throughout the United States. In the Overview, we describe our research team and TACUNA. In the Redesign section, we provide information on how we redesigned the workshops from in person to virtual. In the Recruitment section, we present our recruitment strategies for our virtually delivered workshops and address challenges with male recruitment. Finally, we discuss the implications of our findings of this recruitment approach in the Discussion.

OVERVIEW

Research Team

Our research team, led by Multiple Principal Investigators (MPIs) Drs. Elizabeth D'Amico at RAND and Daniel Dickerson (Inupiaq) at UCLA, worked closely with our community partner, Sacred Path Indigenous Wellness Center (SPIWC), led by Chief Executive Officer (CEO) Dr. Carrie Johnson (Wahpeton Dakota). SPIWC's mission is to ensure research is conducted in a culturally appropriate manner with AI/AN peoples. All team members had extensive expertise working with underserved populations and included individuals with expertise in social media and recruitment. Our team has conducted National Institutes of Health (NIH)-funded research utilizing RCT methodology among urban AI/AN adolescents and adults throughout California and the United States for over 10 years. Our research projects utilizing RCTs have included Motivational Interviewing and Culture for Urban Native American Youth (MICUNAY) (D'Amico et al., 2020), Drum-Assisted Recovery Therapy for Native Americans (DARTNA) (Dickerson et al., 2021b), and our present study, TACUNA (D'Amico et al., 2021; Dickerson et al., 2022).

TACUNA Background

TACUNA is a substance use intervention designed for urban AI/AN emerging adults. TACUNA consists of three workshops that integrate motivational interviewing (MI) with AI/AN traditional practices (D'Amico et al., 2021). This research program is funded under the National Institute of Drug Abuse (NIDA) Helping to End Addiction Long-Term (HEAL) initiative (UG3DA050235, UH3DA050235). Eligibility criteria included: 1) age 18 to 25 years; 2) living in an urban area in any state in the United States (not on a rancheria or a reservation); 3) self-identification as AI/AN; 4) no opioid use disorder; and 5) English speaking. Other than excluding those diagnosed with opioid dependence based on the Rapid Opioid Dependence Screener (Wickersham et al., 2015), we did not include any other substance use eligibility criteria to be inclusive of all ranges of substance use and to help better prevent starting or progressing down the path of unhealthy substance use.

The first year of the grant focused on the final development of TACUNA, utilizing focus groups and a pilot test of TACUNA. Years 2-5 consisted of an RCT analyzing the potential benefits of TACUNA. This research was initially designed before the COVID-19 pandemic, and the RCT was designed to provide in-person groups to urban AI/AN emerging adults in southern, central, and northern California.

A total of 541 participants were enrolled in our study. Eighty-three percent were female and 17% were male, and 53% reported a sexual or gender diverse identity. The mean age was 22.1 (SD 2.2). Participants were enrolled from 37 states, with highest participation rates in California, Arizona, Washington, Oklahoma, and Minnesota. Over 200 tribes were represented in this sample, though no tribal affiliations are reported to protect tribal confidentiality. Very few individuals screened reported having a current opioid use disorder, and these individuals were provided with linkages to treatment.

REDESIGN OF WORKSHOPS FOR VIRTUAL DELIVERY

Similar to the approach used in our MICUNAY study, our initial recruitment strategy included physically sending flyers to community organizations, distributing flyers at community events, advertising our study on community organization websites, and offering bus tokens and transportation options for participants throughout urban areas in California (D'Amico et al., 2020).

Before the COVID-19 pandemic, we completed most of our planned research activities for the developmental year of our study. However, in March 2020, just before pilot testing TACUNA,

the COVID-19 pandemic hit and imposed new restrictions on in-person activities throughout the healthcare field. Many AI/AN organizations and events within AI/AN communities throughout California canceled in-person activities and began to offer cultural programming virtually. To provide an accommodating research strategy to help address the need for programming for these populations, we had to develop new approaches for conducting our RCT to maximize recruitment of urban AI/AN emerging adults into the study. We first conducted meetings with our TACUNA Elder Advisory Board (EAB), SPIWC, and our workshop facilitators for ideas and suggestions. Our EAB consisted of cultural leaders and Elders well-recognized in urban areas throughout the state of California. We were advised that conducting our RCT virtually would be a safe and feasible way to reach our population.

Thus, in April and May of 2020, similar to research teams' approaches highlighted in the recent AIANMHR special edition, we retooled our three in-person TACUNA workshops and our one control workshop, the Health and Wellness Program, by creating virtual versions of both. This included creating virtual versions of our traditional activities (storytelling, cooking, and sage ceremony). We piloted the three TACUNA workshops with several different groups of urban AI/AN emerging adults, who found this approach acceptable and accommodating (Dickerson et al., 2022; Kennedy et al., 2022). As part of this restructuring, we sent all workshop materials by mail. We mailed all handouts and materials to participants, which included cooking ingredients and sage for the traditional activities.

We initially rolled out our study randomizing participants to either TACUNA or the Health and Wellness Program. The TACUNA condition consisted of attending three 2-hour workshops in addition to a 1-hour Wellness Circle. The Wellness Circle is a community-wide event that includes invited speakers who present on a variety of topics that focus on AI/AN traditional practices and wellness. Participants randomized to the Health and Wellness Program were asked to attend one 2-hour health and wellness workshop. This program included content recommended by the National American Indian & Alaska Native Addiction Technology Transfer Center (ATTC) at the University of Iowa (NA-ATTC, n.d.). All respondents also completed follow-up surveys online at 3-, 6-, and 12-month periods after their baseline survey. Respondents were paid \$40 for their first survey, \$60 for their second survey, \$80 for their third survey, and \$100 for their final survey, for a total of \$280. We increased incentives during the trial from \$280 to \$310 to increase participation.

RECRUITMENT ACTIVITIES

Due to various potential barriers to conducting research as mentioned in the Redesign section, we employed elements from the *Broad-Based Coalition of Grassroots Organizations* CBPR model in our recruitment strategy (Weiner & McDonald, 2013). This model consists of a broad array of relationships between researchers with many community-based organizations. MPI Dr. Dickerson (Inupiaq) and SPIWC CEO Dr. Johnson (Wahpeton Dakota) have many pre-established relationships with various AI/AN organizations nationally, which helped our team to successfully engage with urban AI/AN organizations and communities nationwide. In addition, we had an EAB consisting of well-recognized urban AI/AN Elders to help address challenges that arose with recruitment and engaging urban AI/AN emerging adults.

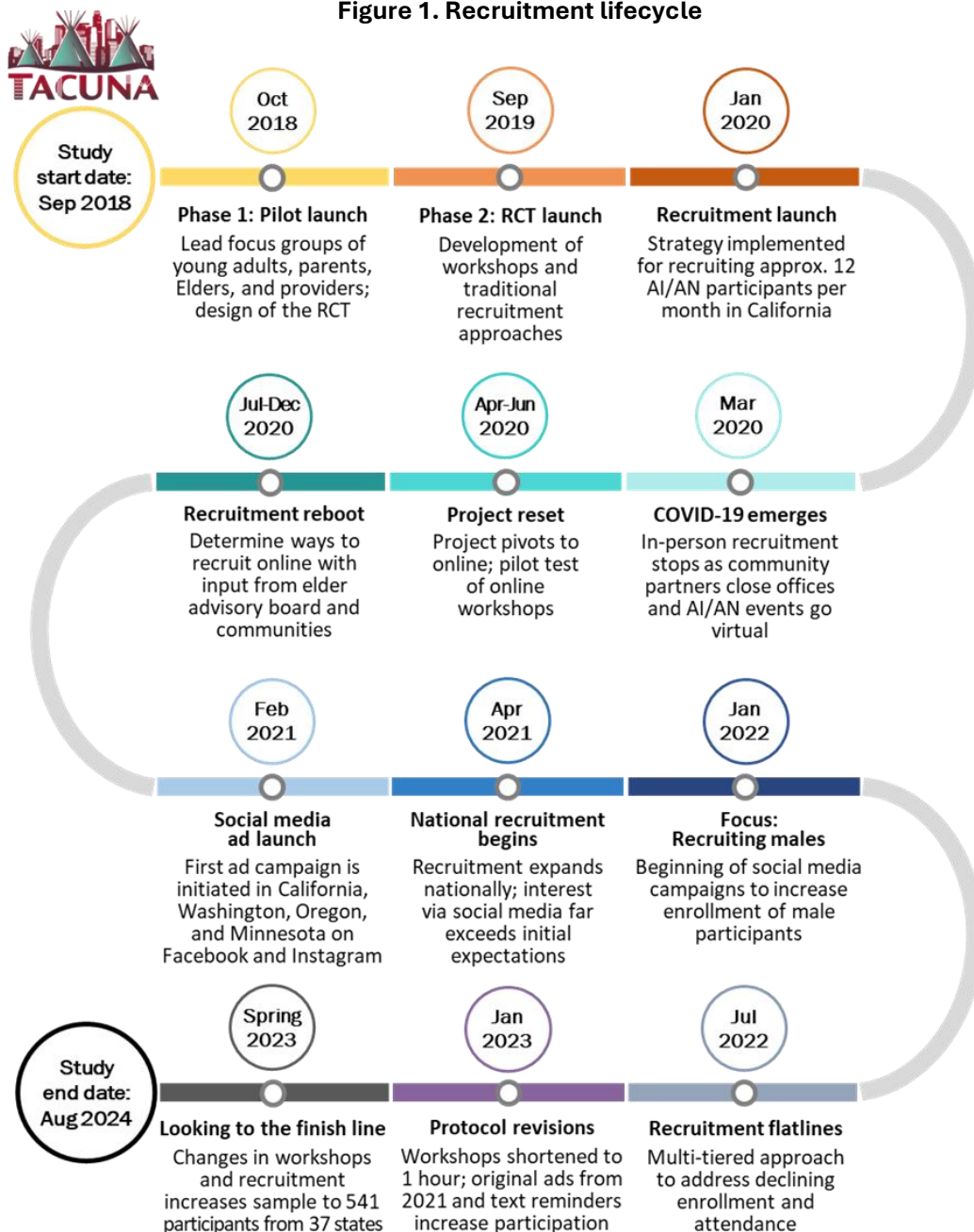
Although substance use prevention was the focus of our study, substance use was introduced gradually during the recruitment process, with the consent form providing full details on the focus of substance use. We chose to use a strengths-based approach emphasizing the resilience of AI/AN people. This approach helped to reduce stigma and to introduce the sensitive nature of substance use in a more culturally appropriate manner.

Substance use was mentioned in all our virtual Facebook and Instagram ads within the visual or descriptive components (e.g., "TACUNA is a research project focused on learning more about urban AI/AN young adults, their social and cultural connectedness, and *substance use*.") The topic of substance use was also mentioned within the description under "What will you be asked to do?". Also, when participants clicked the screener link, they read, "This project focuses on learning more about urban AI/AN young adults, their social and cultural connections, and *substance use*."

As shown in Figure 1, from July to December 2020, we determined ways to recruit online with input from the EAB and AI/AN urban communities. We met with our EAB monthly to discuss various issues and challenges throughout our study. We utilized their input throughout the recruitment process to help enhance ads in terms of AI/AN imagery, content, and description of traditional practices, and to ensure that our ads would resonate with urban AI/AN emerging adults. Due to restrictions imposed by COVID-19 that took place from 2020-2023, we had to pivot and begin an advertising campaign utilizing social media. In January 2021, we designed social media ads. We utilized both Facebook (FB) and Instagram (IG) in our ad campaigns because both utilize algorithms to identify the characteristics and interests of the recruitment population and adjust ads based on reach and response. FB and IG also provide an opportunity to target ads based on content

to one’s intended audience and allow for the use of a combination of advertising approaches, including feeds, stories and reels, in-stream ads, and search results. Feeds provide users with an opportunity to see the most recent posts from their friends. Stories are used to share everyday moments with friends, followers, and individuals that users have chatted with via messages. Reels are short videos with music and audio that users can create and share with friends. In-stream ads are photos or videos that play before, during, or after videos. Searches allow users to type in topics that they are interested in and are searching for on FB or IG.

Figure 1. Recruitment lifecycle



Our ad campaigns on FB and IG ran from seven to 21 days, with the average ad running for two weeks, with a median cost of \$130 per campaign for years 2021 through 2022 and \$60 per campaign in 2023. In Table 1 we report our reach (number of unique users viewing a piece of ad content), impressions (the number of times a piece of content is seen, even if it was not clicked or interacted with), clicks (interactions with our screening website), and costs for each ad campaign. We highlight our recruitment strategies in a timeline format in Figure 1. Figure 2 provides examples of ads used throughout our ad campaigns. Figure 3 provides an example of an ad used to recruit participants who identified as male, as we wanted to boost these numbers. Figure 4 shows a graph with the total number of consents obtained in the study and the number of male participants recruited due to the challenges we experienced recruiting males in this study.

Figure 2. Examples of ads used during the study



Figure 2A.



Figure 2B.



Figure 2C.



Figure 2D.

Figure 3. Example of an ad used to recruit males

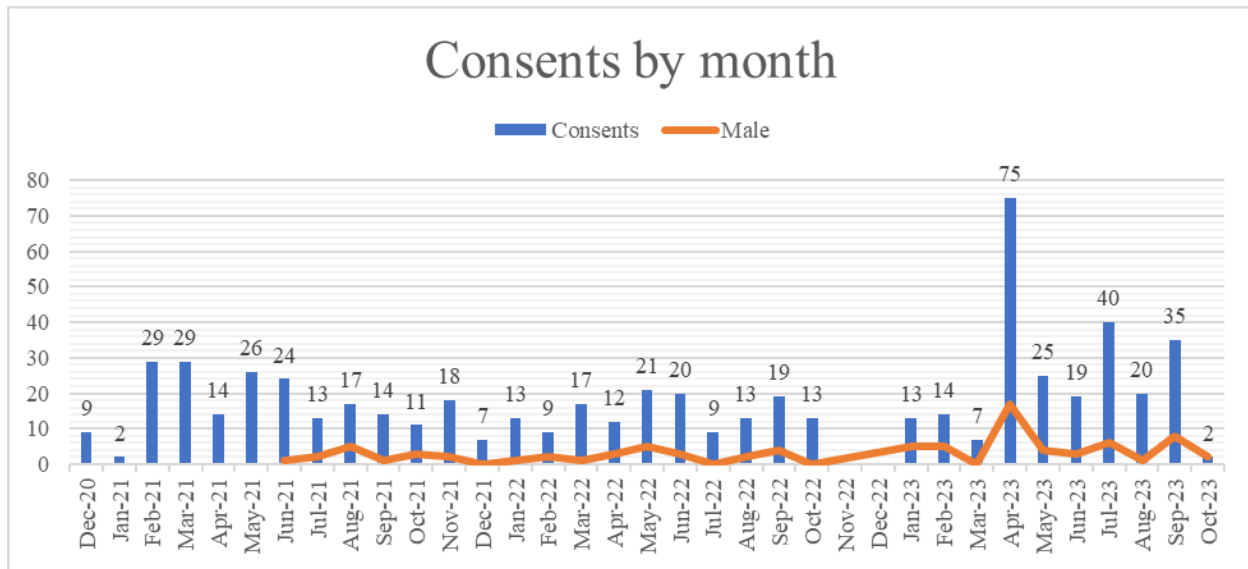


Our virtual recruitment approach consisted of 12 ad campaigns. Each ad campaign posted ads on FB or IG for a set number of days from which we screened and consented a pool of participants. When that participant pool was sufficiently diminished, we ran another campaign. We began our first ad campaign in February 2021 for 13 days and targeted various urban locations throughout the United States, including 18 locations in California, one location in Arizona, one location in Minnesota, one location in Oregon, and one location in Washington state. We matched peoples based on interests in Native American culture in the United States, Native American hoop dance, Native American music, Native American/Indian wisdom, and National Congress of American Indians. We paid \$100 for this ad campaign. We utilized an “ad set bid” approach, which is a category of automated bidding using artificial intelligence that attempts to get the most clicks or conversions. Conversions are a type of advertising that helps to drive a consumer’s actions. Conversions, in our case, were eligible screeners. We let the Meta algorithm on FB decide at what times the ads would show for the best performance. As shown in Table 1, for this first campaign, we had a reach of 10,014 unique users, 20,309 impressions, and 223 clicks. During 2021, we also hired a Native American artist, Santiago Romero, to assist in designing our ads. Examples of ads we used during our first ad campaign are shown in Figures 2a and 2b. As shown in Figure 4, our first ad campaign was successful, far exceeding our expectations. We obtained 29 consents/month in both February and March of 2021.

Table 1.
Ad campaign responses and costs

Campaign	Period	Bid Strategy	Clicks	Reach	Impressions	Cost
February 2021	13 days	Ad set bid	223	10,014	20,309	\$100.00
April 2021	9 days	Lowest cost per clicks	181	8,335	12,348	\$179.22
May 2021	13 days	Ad set bid	316	8,968	16,547	\$100.00
July 2021	13 days	Ad set bid	329	10,883	15,362	\$100.00
October 2021	9 days	Lowest cost per clicks	343	10,624	18,135	\$130.00
March 2022	13 days	Ad set bid	281	15,496	27,882	\$150.00
April 2022	9 days	Ad set bid	512	42,975	62,449	\$291.92
July 2022	13 days	Ad set bid	997	43,054	65,048	\$300.00
March 2023	13 days	Highest volume	665	30,002	40,769	\$225.46
April 2023	13 days	Highest volume	98	5,334	6,051	\$25.38
July 2023	13 days	Highest volume	768	29,952	43,223	\$204.89

Figure 4. Consents per month



In April 2021, we initiated an easier-to-set-up ad campaign for 9 days using a location of the entire United States using FB and IG. We changed our ad type to “lowest cost per clicks” with a set daily limit instead of the “ad set bid” approach used in our first ad campaign. For this ad campaign, we also added animated and video ads. In theory, we believed this approach had the potential to reach a very wide pool of applicants nationwide who would qualify for the study. Our targeted audience was 18-25-year-olds who spoke English and indicated an interest in Native American culture. The size of this audience was 1,100,000. As shown in Table 1, unexpectedly, our number of clicks, impressions, and reach were smaller than our February 2021 ad campaign. Also, as shown in Figure 4, our number of consents was also smaller, with 14 in the month of April.

Due to less success with this easier-to-set-up ad campaign, we decided to repeat our February 2021 approach for our May 2021 ad campaign. We increased our success with 26 consents in May 2021 and 24 consents in June 2021. We also recognized during this time that one ad in particular appeared to receive more responses and was strongly responsible for our successful recruitment (Figure 2a).

In July 2021, we started our fourth ad campaign from July 2021 to September 2021. We continued to use corresponding ads, including our more responsive ad (Figure 2a) and an ad that depicted pictures of urban settings with teepees in the foreground (see Figure 2c). We believed that depicting urban imagery mixed with AI/AN motifs would help to capture the attention of

potential participants. Our approach was moderately successful as we obtained 13, 17, and 14 consents per month, respectively, during this period.

From October 2021 to February 2022, we ran our fifth ad campaign. We only used our most responsive ad (Figure 2a) and a new ad depicting urban imagery with AI/AN motifs (Figure 2c). This approach was moderately successful, and we received a higher number of impressions. However, our consents per month continued to stay low and decreased significantly by the end of the year, as we only received 7 consents in December 2021.

From March 2022 to the end of the study, we streamlined our approach based on what we believed worked best, which included using primarily our most responsive ad (Figure 2a) and new ads to help increase recruitment for participants who identified as male (explained below). In the last year of our recruitment, starting in January 2023, to enhance retention, we also shortened our workshops from 2 hours to 1 hour based on feedback from participants (Palimaru et al., 2024). In conjunction with this change in our workshop length, we also created reels (short videos) on IG instead of static fliers to try to get more views, which we hoped would be more engaging to the viewer (see Figure 2d). As shown in Figure 4, we had substantial success at 75, 40, and 35 consents in the months of April 2023, July 2023, and September 2023, respectively. During these three months, we also added “study ending soon,” which may have helped to increase recruitment.

Overall, our original ad (Figure 2a) was the most successful, with a total of 3,860 clicks across recruitment, a percentage of 70% of total clicks across all 12 ad campaigns, a reach of 154,415 unique users, and 229,757 impressions. The ad was designed by co-author Ninna Gudgell and outperformed all other ads used consistently across the recruitment period. A graphics interchange format (gif) version of the ad was used in April 2021 and received about half the reach and a quarter of the clicks as the static image. Updates were made in July 2022 to reflect an increase in the possible incentive. Otherwise, the original ad design was left untouched.

Approaching Low Male Recruitment

In early 2022 we noticed a persistent pattern of low male recruitment. In February 2022 we held discussions with our EAB to help gather insights into potential reasons for their lower representation. One idea the EAB postulated was *toxic masculinity* and lower interest levels from males in participating in AI/AN traditional activities. Toxic masculinity refers to strict rules that prescribe what a man should be, which includes a reluctance to engage in behavioral-oriented interventions (Staiger et al., 2020). Further, traditional masculinity is often characterized by substance use and risk-taking behaviors (Klingermann & Klingermann, 2023). Our TACUNA

EAB provided suggestions to help enhance male engagement. They suggested inviting more male Wellness Circle presenters for our program and to depict more males in our advertising to help connect with this audience. In March 2022, we hired a well-known Native American graphic artist, Paige Smith (Paiute, Modoc-Enrolled Klamath Tribes), to assist with creating ads to help generate more interest among urban AI/AN emerging adult males. In April 2022, we tested a new ad with an image of Paige Smith, to depict an AI/AN male, thereby hopefully helping to increase male recruitment (See Figure 3). This ad generated 252 link clicks with a reach of 18,764. The gender distribution was 34% male and 64% female, with nearly 85% of activity coming from FB. We also added more male Wellness Circle presenters, including an AI/AN comedian and traditional practitioners. These approaches helped sustain male recruitment trends; however, the percentage of males who enrolled in this study stayed consistently below those of females (see Figure 4). In July 2022, we also posted an ad campaign using our most responsive ad in conjunction with new ads designed by Paige Smith depicting males to help enhance male recruitment. Utilizing this combination, we had more clicks and similar reach and impressions. We continued to include more males in our ads for the remainder of our study and increased the number of male Wellness Circle presenters. Similar to females, we observed a mild increase in male recruitment, with more success in the last year of our study. Given the changes we made to recruit and conduct our RCT virtually, we were able to surpass our original recruitment goal of 370 with a final recruitment of 541 AI/AN emerging adults who lived in 37 states.

DISCUSSION

Our study fills a critical gap in developing strategies to recruit urban AI/AN emerging adults for substance use interventions through the use of virtual methodologies. The COVID-19 pandemic created unexpected challenges to recruiting participants into RCTs from underserved communities, requiring new creative and innovative strategies. By “going virtual,” we were able to broaden our recruitment nationally and demonstrate the effectiveness of recruiting virtually for an RCT among a population where substance use intervention research has been scarce. Our FB and IG ad campaigns helped us surpass our original recruitment goal and obtain 541 AI/AN emerging adults who lived in urban areas spanning 37 states. Using CBPR strategies were critical to our success as we capitalized on previously established relationships with community partners. Their buy-in and ability to advocate for our study helped increase comfort in participation in a study on substance use prevention. Our strengths-based approach using virtual ads highlighting

the role of participating in AI/AN traditional practices and healthy social connections helped to decrease stigma associated with substance use known to exist within these populations, resulting in highly successful recruitment of urban AI/AN emerging adults into our study. As a result, findings generated from our study are not only more generalizable but also may have greater potential for influencing policy as they can bring attention to the substance use intervention needs of a large segment of the AI/AN population that has been less engaged in research.

We noted many notable advantages to recruitment virtually with very few disadvantages. One notable advantage to virtual recruitment was our ability to broaden our recruitment nationally. Similar to Sinclair et al., 2022, who conducted a study of a diabetes prevention intervention for AI/AN men, by delivering our intervention virtually, we were able to open up our study to participants across the United States. Increasing our recruitment pool nationally within urban areas also offered us an opportunity to obtain data that are more generalizable among the tribally diverse population of AI/AN emerging adults, thereby aiding in the potential for wider-scale implementation of TACUNA. Receiving buy-in nationally validates the broad appeal of TACUNA's acceptability among a very tribally diverse population.

Next, with virtual recruitment, we were able to more creatively reach our selected population. Using algorithms available on FB and IG, we could determine which ads were responsible for a higher number of participant consents, which then helped us adjust our ad campaigns to reach more participants. In addition, another advantage of initiating campaign ads using social media was the ability to target ads based on specific audience characteristics and interests. Creating our ads utilizing algorithms helped capture audiences with interests in AI/AN culture who resided in urban areas, resulting in high numbers of clicks and impressions.

Data from our ad campaigns identified one ad that attracted much more attention and was responsible for participants completing a screening and consent than all other ads (Figure 2a). It is possible that the more traditional AI/AN-themed colors and design used in this ad may have been more appealing to participants. Also, the wording used in the ad, including the clear and brief explanation of the study, may have helped increase participant interest. For future studies using virtual technologies, we recommend identifying ads "that work" via these algorithms as it can help research teams meet recruitment goals more quickly, particularly among more difficult-to-reach populations.

Virtual-based recruitment helped to address logistical barriers to participating in RCTs within urban areas among this population including transportation and childcare. In a previously conducted pilot test of TACUNA, feedback from participants suggested that providing workshops

virtually can help urban AI/AN emerging adults attend sessions who may not be able to due to financial and logistical constraints (Dickerson et al., 2022). Furthermore, the burden on research staff was much less with our virtual recruitment approach. Virtual recruitment is much less cumbersome in comparison to physical-based recruitment, which requires physically placing flyers within organizations and at community events and which may require changing, printing, and mailing new flyers to community-based organizations.

We found very few “cons” with virtual recruitment in our study that are typically experienced with this approach (Hoeflich et al., 2022). For example, we did not experience overt technical and structure issues in our recruitment, nor were confidentiality or privacy concerns expressed to our team. Stigmatization of substance use and of being overheard during the recruitment also did not appear to be a barrier to virtual recruitment. We suggest future studies utilizing virtual recruitment approaches address these potential issues in their virtual recruitment strategy.

Overall, we saw that clicks were much higher than actual enrollment numbers. It is possible that the imagery, colors, and depiction of AI/AN emerging adults were “eye-catching” and caught the interests of these populations. However, a large difference was found between the number of impressions and the actual number of participants who consented into the study. Research is needed to better understand ways to increase actual enrollment. One thing that may have helped increase enrollment from clicks was if we used our ads to better highlight creating social connections within urban communities.

The recruitment of males into our study was challenging. We attempted to address this by initiating a more targeted approach with more male-centered ads and including more male presenters in our Wellness Circles. We did increase male recruitment; however, trends were similar to females, thus, we still had significantly more females in the study. Our experience with the recruitment of males was in contrast to Sinclair et al. (2022), who were more successful. Their approach included creating multiple posts daily, emphasizing the strength, roles, and importance of men in AI/AN communities and for them to be healthy in their role within the community. Creating strength-based recruitment ad strategies for substance use intervention studies highlighting the important role of men within AI/AN communities and involvement in traditional practices may decrease the stigma associated with substance use among these populations, combat the possible effects of toxic masculinity, and result in more successful male recruitment. A recent qualitative study among Indigenous peoples in Canada to combat the effectiveness of colonialism showed that cultural strengths and engaging in ceremonies and role modeling were critical

components of the healing journey to mental wellness for Indigenous men (Waddell et al., 2021). Colonialism has also been highlighted as having a detrimental effect by redefining the role of AI/AN men by strictly limiting the roles as providers and protectors and impacting them internally (psychologically) and externally (rationally) (Bauman, 2024). Further research is needed to identify methods that can help increase the recruitment of urban AI/AN emerging adult males into RCTs analyzing new substance use interventions.

Limitations

Although this study showcased the utility of social media recruitment strategies to reach urban AI/AN emerging adults nationally across 37 states, this study was conducted following the outbreak of the COVID-19 pandemic and was not originally designed to be a nationwide study. Also, we did not have a gender break-down on the numbers of clicks, reach, and impressions, which may have helped to further explain differences in lower male recruitment observed in this study. Further research is recommended to determine ways to increase reach across different states within urban areas of the United States. More articulated research goals and a research design set to analyze the potential benefit of virtually based recruitment strategies among these populations are, thus, recommended.

CONCLUSION

Overall, pivoting to online implementation delivery and recruitment provided a unique opportunity to demonstrate the benefits of utilizing virtual approaches to recruit urban AI/AN emerging adults into RCT studies analyzing new substance use interventions. Findings highlight the advantages of using FB and IG algorithms to identify the characteristics and interests of our recruitment population and to modify ads based on reach. Through our innovative recruitment strategies, we were able to overcome the logistical barriers of in-person recruitment during the COVID-19 pandemic and obtain a large representative sample of urban AI/AN emerging adults. This critical change may help us to better understand the potential benefits of promising new substance use interventions for these populations, which may help decrease the impact of substance use among this population.

REFERENCES

- Bauer, C., Hassan, G. H., Bayly, R., Cordes, J., Bernson, D., Woods, C., Li, X., Li, W., Ackerson, L. K., Larochelle, M. R., & Stopka, T. J. (2024). Trends in fatal opioid-related overdose in American Indian and Alaska Native communities, 1999–2021. *American Journal of Preventive Medicine*, 66(6). <https://doi.org/10.1016/j.amepre.2024.01.019>
- Baumann, D. (2024). Beyond fistfights and basketball: Reclaiming Native American masculinity. *Humans*, 4(2), 200–211. <https://doi.org/10.3390/humans4020012>
- Blue Bird Jernigan, V., Peercy, M., Branam, D., Saunkeah, B., Wharton, D., Winkleby, M., Lowe, J., Salvatore, A. L., Dickerson, D., Belcourt, A., D’Amico, E., Patten, C. A., Parker, M., Duran, B., Harris, R., & Buchwald, D. (2015). Beyond health equity: Achieving wellness within American Indian and Alaska Native communities. *American Journal of Public Health*, 105(S3), S376–S379. <https://doi.org/10.2105/ajph.2014.302447>
- Brave Heart, M.Y. & DeBruyn, L.M. (1998). The American Indian holocaust: healing historical unresolved grief. *American Indian Alaska Native Mental Health Research*, 8(2), 56-78. <https://doi.org/10.5820/aian.0802.1998.60>
- Brockie, T. N., Hill, K., Davidson, P. M., Decker, E., Krienke, L. K., Nelson, K. E., Nicholson, N., Werk, A. M., Wilson, D., & Around Him, D. (2022). Strategies for culturally safe research with Native American communities: An integrative review. *Contemporary Nurse*, 58(1), 1–25. <https://doi.org/10.1080/10376178.2021.2015414>
- Brown, R. A., Dickerson, D. L., Klein, D. J., Agniel, D., Johnson, C. L., & D’Amico, E. J. (2019). Identifying as American Indian/Alaska Native in urban areas: Implications for adolescent behavioral health and well-being. *Youth & Society*, 53(1), 54–75. <https://doi.org/10.1177/0044118x19840048>
- Burt, L.W. (1986). Roots of the Native American urban experience: Relocation policy in the 1950s. *American Indian Quarterly*, 10(2), 85-99.
- Center for Behavioral Health Statistics and Quality. (2024). 2022 National survey on drug use and health: Among the American Indian or Alaska Native (AI/AN) population aged 12 or older. Substance Abuse and Mental Health Services Administration. <https://www.samhsa.gov/data/sites/default/files/reports/rpt44472/2022-nsduh-pop-slides-aian.pdf>

- Crump, A. D., Etz, K., Arroyo, J. A., Hemberger, N., & Srinivasan, S. (2017). Accelerating and strengthening Native American health research through a collaborative NIH initiative. *Prevention Science*. <https://doi.org/10.1007/s11121-017-0854-5>
- D'Amico, E. J., Dickerson, D. L., Brown, R. A., Johnson, C. L., Klein, D. J., & Agniel, D. (2020). Motivational Interviewing and Culture for Urban Native American youth (MICUNAY): A randomized controlled trial. *Journal of Substance Abuse Treatment*, *111*, 86–99. <https://doi.org/10.1016/j.jsat.2019.12.011>
- D'Amico, E. J., Dickerson, D. L., Rodriguez, A., Brown, R. A., Kennedy, D. P., Palimaru, A. I., Johnson, C., Smart, R., Klein, D. J., Parker, J., McDonald, K., Woodward, M. J., & Gudgell, N. (2021). Integrating traditional practices and social network visualization to prevent substance use: study protocol for a randomized controlled trial among urban Native American emerging adults. *Addiction Science & Clinical Practice*, *16*(1). <https://doi.org/10.1186/s13722-021-00265-3>
- Dickerson, D., Baldwin, J. A., Belcourt, A., Belone, L., Gittelsohn, J., Keawe'aimoku Kaholokula, J., Lowe, J., Patten, C. A., & Wallerstein, N. (2018). Encompassing cultural contexts within scientific research methodologies in the development of health promotion interventions. *Prevention Science*, *21*(S1), 33–42. <https://doi.org/10.1007/s11121-018-0926-1>
- D. L., D'Amico, E. J., Klein, D. J., Johnson, C. L., Hale, B., & Ye, F. (2020). Mental health, physical health, and cultural characteristics among American Indians/Alaska Natives seeking substance use treatment in an urban setting: A descriptive study. *Community Mental Health Journal*. <https://doi.org/10.1007/s10597-020-00688-3>
- Dickerson, D. L., D'Amico, E. J., Klein, D. J., Johnson, C. L., Hale, B., Ye, F., & Dominguez, B. (2021). Drum-assisted recovery therapy for Native Americans (DARTNA): Results from a feasibility randomized controlled trial. *Journal of Substance Abuse Treatment*, 108439. <https://doi.org/10.1016/j.jsat.2021.108439>
- Dickerson, D. L., Parker, J., Johnson, C. L., Brown, R. A., & D'Amico, E. J. (2020). Recruitment and retention in randomized controlled trials with urban American Indian/Alaska Native adolescents: Challenges and lessons learned. *Clinical Trials*, *18*(1), 83–91. <https://doi.org/10.1177/1740774520971774>

- Dickerson, D. L., D'Amico, E. J., Palimaru, A., Brown, R., Kennedy, D., Johnson, C. L., & Schweigman, K. (2022). Traditions and Connections for Urban Native Americans (TACUNA): Utilizing community-based input to develop an opioid prevention intervention for urban American Indian/Alaska native emerging adults. *Journal of Substance Abuse Treatment, 139*, 108764. <https://doi.org/10.1016/j.jsat.2022.108764>
- Frost, R. H. (1996). Review of deadly medicine: Indians and alcohol in early America. *Bulletin of the History of Medicine, 70*(3), 531-531.
- Hirschak, K. A., Nadeau, M., Vasquez, A., Hernandez-Vallant, A., Smith, K., Pham, C., Oliver, K. A., Baukol, P., Lizzy, K., Shaffer, R., Herron, J., Campbell, A. N. C., & Venner, K. L. (2022). Centering culture in the treatment of opioid use disorder with American Indian and Alaska Native communities: Contributions from a national collaborative board. *American Journal of Community Psychology. https://doi.org/10.1002/ajcp.12620*
- Hoeflich, C. C., Wang, A., Otufowora, A., Cottler, L. B., & Striley, C. W. (2022). Virtual recruitment and participant engagement for substance use research during a pandemic. *Current Opinion in Psychiatry, 35*(4), 252–258. <https://doi.org/10.1097/ycp.0000000000000794>
- Hunter, A., Richards, J., Ali-Joseph, A., & Camplain, C. (2022). Between two worlds: Impacts of COVID-19 on the AI/AN health research workforce. *American Indian and Alaska Native Mental Health Research, 29*(2). <https://doi.org/10.5820/aian.2902.2022.183>
- James, R. D., West, K. M., Claw, K. G., EchoHawk, A., Dodge, L., Dominguez, A., Taulii, M., Forquera, R., Thummel, K., & Burke, W. (2018). Responsible research with urban American Indians and Alaska Natives. *American Journal of Public Health, 108*(12), 1613–1616. <https://doi.org/10.2105/ajph.2018.304708>
- Kelley, A., Small, C., Milligan, K., & Charani Small, M. (2022). Rising above: COVID-19 impacts to culture-based programming in four American Indian communities. *American Indian and Alaska Native Mental Health Research, 29*(2). <https://doi.org/10.5820/aian.2902.2022.49>

- Kennedy, D. P., D’Amico, E. J., Brown, R. A., Palimaru, A. I., Dickerson, D. L., Johnson, C. L., & Lopez, A. (2022). Feasibility and acceptability of incorporating social network visualizations into a culturally centered motivational network intervention to prevent substance use among urban Native American emerging adults: A qualitative study. *Addiction Science & Clinical Practice*, 17(1). <https://doi.org/10.1186/s13722-022-003341>
- Klingemann, J. I., & Klingemann, H. (2023). Masculinity and addiction: A narrative review of therapeutic interventions for men with substance-use disorders. *Alkoholizm I Narkomania*, 36(3), 207–220. <https://doi.org/10.5114/ain.2023.134777>
- Maudrie, T., Nguyen, C., Blue Bird Jernigan, V., Lessard, K., Richardson, D., Gittelsohn, J., & O’Keefe, V. (2022). Impacts of COVID-19 on a food security study with the Baltimore Native community. *American Indian and Alaska Native Mental Health Research*, 29(2). <https://doi.org/10.5820/aian.2902.2022.8>
- Mello, M. M., & Wolf, L. E. (2010). The Havasupai Indian Tribe Case — Lessons for research involving stored biologic samples. *New England Journal of Medicine*, 363(3), 204–207. <https://doi.org/10.1056/nejmp1005203>
- National American Indian & Alaska Native Addiction Technology Transfer Center (NA-ATTC). Tribal Opioid Response (TOR) Program <https://attcnetwork.org/centers/national-american-indian-and-alaska-native-attc/home>
- Oberly, J., & Macedo, J. (2004). The R word in Indian Country: Culturally appropriate commercial tobacco-use research strategies. *Health Promotion Practice*, 5(4), 355–361. <https://doi.org/10.1177/1524839904267391>
- Palimaru, A. I., Brown, R. A., Dickerson, D. L., Kennedy, D., Johnson, C. L., & D’Amico, E. J. (2023). Mixed methods evaluation of satisfaction with two culturally tailored substance use prevention programs for American Indian/Alaska Native emerging adults. *Prevention Science*. <https://doi.org/10.1007/s11121-023-01612-3>
- Patel, H., Masten, K., Chambers, R., Edwards, A., Fleszar, L., Harvey, B., Dunn, J., Nelson, D., Goldtooth, T., James, M., Huskon, R., Tsosie, A., Richards, J., & Tingey, L. (2022). Feasibility and acceptability of virtual implementation of a sexual reproductive health teen pregnancy prevention program for Native youth. *American Indian and Alaska Native Mental Health Research*, 29(2). <https://doi.org/10.5820/aian.2902.2022.63>

- Petereit, D. G., Guadagnolo, B. A., Wong, R., & Coleman, C. N. (2011). Addressing cancer disparities Among American Indians through innovative technologies and patient navigation: The Walking Forward Experience. *Frontiers in Oncology, 1*. <https://doi.org/10.3389/fonc.2011.00011>
- Planalp, C., Au-yeung C.M., & Winkelman T.N.A. (2021). Escalating alcohol-involved death rates: Trends and variation across the nation and in the states from 2006 to 2019. The State Health Access Data Assistance Center (SHADAC), pp. 1–9.
- Rink, E., Johnson, O., Anastario, M., Firemoon, P., Peterson, M., & Baldwin, J. (2022). Adaptations due to the COVID-19 pandemic in a community-based participatory research randomized control trial examining sexual and reproductive health outcomes among American Indian youth. *American Indian and Alaska Native Mental Health Research, 29*(2). <https://doi.org/10.5820/aian.2902.2022.32>
- Rink, E., Knight, K., Ellis, C., McCormick, A., FireMoon, P., Held, S., Webber, E., & Adams, A. (2020). Using community-based participatory research to design, conduct, and evaluate randomized controlled trials with American Indian communities. *Preventing Chronic Disease, 17*. <https://doi.org/10.5888/pcd17.200099>
- Sahota, P., Contreras, A., Kastelic, S., Cross-Hemmer, A., Black, A. Y., Cross, T., Personius, D. J., Pecora, P., Kinswa-Gaiser, P., & Him, D. A. (2022). Positive Indian Parenting: A unique collaborative study in the age of COVID-19. *American Indian and Alaska Native Mental Health Research, 29*(2). <https://doi.org/10.5820/aian.2902.2022.104>
- Sinclair, K., Nikolaus, C., Gillespie, L., Garza, C., Pahona, W., Blaz, J., & Buchwald, D. (2022). Strong men, strong communities: Revision of a diabetes prevention intervention for American Indian and Alaska Native men during the COVID-19 pandemic. *American Indian and Alaska Native Mental Health Research, 29*(2). <https://doi.org/10.5820/aian.2902.2022.85>
- Skewes, M. C., Gonzalez, V. M., Gameon, J. A., FireMoon, P., Salois, E., Rasmus, S. M., Lewis, J. P., Gardner, S. A., Ricker, A., & Reum, M. (2020). Health disparities research with American Indian communities: The importance of trust and transparency. *American Journal of Community Psychology, 66*(3-4), 302–313. <https://doi.org/10.1002/ajcp.12445>

- Soto, C., West, A. E., Ramos, G. G., & Unger, J. B. (2022). Substance and behavioral addictions among American Indian and Alaska Native populations. *International Journal of Environmental Research and Public Health*, 19(5), 2974. <https://doi.org/10.3390/ijerph19052974>
- Staiger, T., Stiawa, M., Mueller-Stierlin, A. S., Kilian, R., Beschoner, P., Gündel, H., Becker, T., Frasch, K., Panzirsch, M., Schmauß, M., & Krumm, S. (2020). Masculinity and help-seeking among men with depression: A qualitative study. *Frontiers in Psychiatry*, 11(11). <https://doi.org/10.3389/fpsy.2020.599039>
- Steinberg, R.I., Begay, J.A., Begay, P.M., Goldtooth, D.L., Nelson, S.T.M., Yazzie, D.A., Delamater, A.M., Hockett, C.W., Phimphasone-Brady, P., Powell, J.C., Sinha, M., Dabelea, D., & Sauder, K.A. (2022). Lessons on resilient research: Adapting the Tribal Turning Point Study to COVID-19. *American Indian Alaska Native Mental Health Research*, 29(2), 155-182. <https://doi.org/10.5820/aian.2902.2022.155>
- Urban Indian Health Commission. Invisible Tribes: Urban Indians and Their Health in a Changing World. Seattle: Urban Indian Health Commission, 2007.
- U.S. Census Bureau History: American Indians and Alaska Natives. (2021). U.S. Census Bureau. https://www.census.gov/history/www/homepage_archive/2021/november_2021.html
- Waddell, C.M., de Jager, M.D., Gobeil, J., Tacan, F., Herron, R.V., Allan, J.A., & Roger, K. (2021). Healing journeys: Indigenous men's reflections on resources and barriers to mental wellness. *Social Science & Medicine*, 270, 113696. <https://doi.org/10.1016/j.socscimed.2021.113696>
- Weaver, H.N. (2012). Urban and Indigenous: The challenges of being a Native American in the city. *Journal of Community Practice*. 20(4), 470–488. <https://doi.org/10.1080/10705422.2012.732001>
- Weiner, J. & McDonald, J.A. (2013). Special issue: Three models of community-based participatory research. *LDI Issue Brief*, 18(5):1-8.

- Wells, C., White, L., Schmidt, T., Rataj, S., McEachern, D., Wisnieski, D., Garnie, J., Kirk, T., Moto, R., & Wexler, L. (2022). Adapting PC CARES to continue suicide prevention in rural Alaska during the COVID-19 pandemic: Narrative overview of an in-person community-based suicide prevention program moving online. *American Indian and Alaska Native Mental Health Research*, 29(2). <https://doi.org/10.5820/aian.2902.2022.126>
- Wickersham, J. A., Azar, M. M., Cannon, C. M., Altice, F. L., & Springer, S. A. (2015). Validation of a brief measure of opioid dependence: The Rapid Opioid Dependence Screen (RODS). *Journal of Correctional Health Care: The Official Journal of the National Commission on Correctional Health Care*, 21(1), 12–26. <https://doi.org/10.1177/1078345814557513>
- Wolf, A.S. (1989). The Barrow studies: An Alaskan's perspective. *American Indian Alaska Native Mental Health Research*, 2(3), 35-40. <https://doi.org/10.5820/aian.0203.1989.35>
- Yuan, N.P., Bartgis, J., & Demers, D. (2014). Promoting ethical research with American Indian and Alaska Native people living in urban areas. *American Journal of Public Health*, 104(11), 2085. <https://doi.org/10.2105/AJPH.2014.302027>

ACKNOWLEDGMENTS

We would like to acknowledge our urban-based community partners across the United States and all urban AI/AN emerging adults who participated in our study. We would also like to thank our TACUNA Elder Advisory Board, RAND Survey Research Group (SRG), and broader TACUNA research team members for their participation in supporting this project. We would also like to thank Santiago Romero for his contributions in creating ads for this study.

CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

FUNDING

This study was supported by National Institute on Drug Abuse (NIDA) (UH3DA050235; PIs: Drs. Elizabeth D’Amico and Daniel Dickerson). The content is solely the responsibility of the

authors and does not necessarily represent the official views of the National Institutes of Health, its NIH HEAL Initiative, or the U.S. Department of Health and Human Services or any of its affiliated institutions or agencies.

AUTHOR INFORMATION

Daniel L. Dickerson, DO, MPH (Inupiaq), is an Associate Research Psychiatrist at the Integrated Substance Use and Addiction Programs (ISAP) at the University of California, Los Angeles in Los Angeles, CA.

Mel Borstad, MA, is a Survey Coordinator I at RAND in Santa Monica, CA.

Ninna Gudgell, BA, is a Division Administrator at RAND in Santa Monica, CA.

Keisha McDonald, BS, is a Senior Survey Coordinator at RAND in Santa Monica, CA.

Jennifer Parker, BA, is an Associate Survey Director at RAND in Santa Monica, CA.

Paige Smith, CPS, CADC-1 (Paiute, Modoc-Enrolled Klamath Tribes), is a Consultant at Sacred Path Indigenous Wellness Center in Anaheim, CA.

Pierrce Holmes, MA, is a Policy Analyst at RAND in Boston, MA.

Michael J. Woodward, is a Research Project Manager at RAND in Santa Monica, CA.

Carrie L. Johnson, PhD (Wahpeton Dakota), is Chief Executive Officer at Sacred Path Indigenous Wellness Center in Anaheim, CA.

Elizabeth J. D'Amico, PhD, is a Senior Behavioral Scientist at RAND in Santa Monica, CA.