

CAIANDTR PILOT & FEASIBILITY PROGRAM

LIST OF DATA SETS FOR SECONDARY ANALYSIS

Compiled here is a list of data sets that have been used by CAIANDTR Pilot Grant Awardees, as well as other data sets that may include data relevant to diabetes in Native populations. This list is not exhaustive and is just meant to provide examples of data sets for secondary analysis projects. Applicants may use one of the data sets listed here but are not required to.

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DATA SETS USED IN CAIANDTR PILOT STUDIES (2017-2024)

PILOT INVESTIGATOR	DATA SOURCE(S)	POPULATION(S)	EXAMPLE MEASURES	PUBLICATION/REFERENCE
Kaipeng Wang	Behavioral Risk Factor Surveillance System (BRFSS)	American Indian adults with diabetes	Mental health; self-management behaviors (blood sugar testing, foot exams, diabetes management courses, self-monitoring of blood glucose, physical activity, routine health care visits)	In progress

PILOT INVESTIGATOR	DATA SOURCE(S)	POPULATION(S)	EXAMPLE MEASURES	PUBLICATION/REFERENCE
Li Chao	Strong Heart Study	American Indian adults with diabetes who were enrolled in the Strong Heart Study from Phases 1 to 6 (1988-2018)	HbA1c, fasting glucose, 2-h glucose, HOMA-IR and serum lipids, including LDL, HDL and TG	In progress
Ginny Lane	SEARCH for Diabetes in Youth Study	Identified youth aged 0-19 years with a physician diagnosis of type 1 or type 2 diabetes at five centers in the USA between 2002 and 2018	Risk factors for diabetic ketoacidosis	In progress
Susie Lopez	Chickasaw Healthy Eating Environments in Retail Stores (CHEERS)	American Indian adults who participated in the CHEERS study	Food insecurity, depression, alcohol use, tobacco use	In progress
Erin Morgan	Strong Men, Strong Community (SMSC)	American Indian men who participated in the SMSC study	Perceptions of masculinity, diabetes prevention strategies (diet, exercise, healthcare engagement)	In progress
Maja Pederson	Semi-structured qualitative interviews	Rural American Indian adults (50-82 years)	Physical activity behaviors	In progress
Brandon Varilek	United States Renal Data System	AI/ANS and NHWs with end-stage renal disease (ESRD) related to diabetes	ESRD diagnosis, kidney transplant, hospice referrals	In progress
Liz Anderson	IHS Improving Health Care Delivery Data Project (“IHS Data Project”)	AI/AN and White Medicare Beneficiaries aged ≥65 years in 2019 and who died in 2019	Health service use, demographics, health coverage, health status, SDOHs	In progress

PILOT INVESTIGATOR	DATA SOURCE(S)	POPULATION(S)	EXAMPLE MEASURES	PUBLICATION/REFERENCE
Luciana (Lucy) Hebert	Pregnancy Risk Assessment Monitoring System (PRAMS) (Phase 8; 2016-2018)	Women with GDM from different racial/ethnic groups in five states (Alaska, Oklahoma, New Mexico, South Dakota, and Washington)	GDM, breastfeeding initiation, sociodemographics	Hebert, L. E., Nikolaus, C. J., Zamora-Kapoor, A., & Sinclair, K. A. (2022). Gestational diabetes and breastfeeding among women of different races/ethnicities: Evidence from the Pregnancy Risk Assessment Monitoring Surveys. <i>Journal of Racial and Ethnic Health Disparities</i> , 10, 1721–1734. https://doi.org/10.1007/s40615-022-01356-w Watch this webinar to learn more
Cassandra Nguyen (Nikolaus)	National Longitudinal Study of Adolescent to Adult Health (Wave 4; 2008-2009)	Wave 4 cohort members who were 24–32 years old	Risk of food insecurity, indicators of cardiometabolic health (body mass index, hemoglobin A1c, blood pressure), sociodemographic characteristics	Nikolaus, C. J., Zamora-Kapoor, A., Hebert, L. E., & Sinclair, K. (2022). Association of food security with cardiometabolic health during young adulthood: Cross-sectional comparison of American Indian adults with other racial/ethnic groups. <i>BMJ Open</i> , 12(6), e054162. https://doi.org/10.1136/bmjopen-2021-054162
Christine Hockett	SEARCH for Diabetes in Youth (2002-2016) US Census Data, 2010 American Community Survey (2010)	Youth aged 0-19 years with T2D and who were active users of tribally operated or IHS-operated regional health facilities	Economic stability, neighborhood & physical environment, education, health & healthcare system, community & social context	Watch this webinar to learn more Or review the webinar slides
Sarah Stotz	Data were collected in August–October 2018 through focus groups and interviews with AI/AN adults with T2D and additional stakeholders	AI/AN adults with T2D, adult family members, community-based key participants, national content experts	Example interview guide question: ‘Tell me what it’s like to learn about diabetes and nutrition in your community’	Stotz, S., Brega, A. G., Henderson, J. N., Lockhart, S., & Moore, K. (2021). Food insecurity and associated challenges to healthy eating among American Indians and Alaska Natives with type 2 diabetes: Multiple stakeholder perspectives. <i>Journal of Aging and Health</i> , 33(7-8_suppl), 31s-39s. https://doi.org/10.1177/08982643211013232

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<p>Cheryl Conway (with Amber Fyfe-Johnson, Vanessa Hiratsuka, Kimberly Huyser, Michelle Johnson-Jennings)</p>	<p>IHS Improving Health Care Delivery Data Project (“IHS Data Project”); FY 2013</p> <p>US Census Data, American Community Survey (2010-2014)</p> <p>USDA Food Environment Atlas</p> <p>National Center for Health Statistics</p>	<p>AI/AN adults aged ≥ 50 years who used IHS/tribal services in FY2013</p>	<p>IHS Data Project BMI, demographics, health coverage, health care access</p> <p>ACS/Food Environment Atlas SDOH indicators</p> <p>NCHS Rural/urban</p>	<p>Goins, R. T., Conway, C., Reid, M., Jiang, L., Chang, J., Huyser, K. R., Brega, A. G., Steiner, J. F., Fyfe-Johnson, A. L., Johnson-Jennings, M., Hiratsuka, V., Manson, S. M., & O’Connell, J. (2022). Social determinants of obesity in American Indian and Alaska Native peoples aged ≥ 50 years. <i>Public Health Nutrition</i>, 25(8), 1-30. https://doi.org/10.1017/s1368980022000945</p>
<p>Amber Fyfe-Johnson (with Cheryl Conway, Vanessa Hiratsuka, Kimberly Huyser, Michelle Johnson-Jennings)</p>	<p>IHS Improving Health Care Delivery Data Project (“IHS Data Project”); FYs 2007–2013</p> <p>US Census Data, American Community Survey (2010-2014)</p> <p>USDA Food Environment Atlas</p> <p>National Center for Health Statistics</p>	<p>AI/AN children 2–11 years of age, who used IHS from 2010 to 2014</p>	<p>IHS Data Project BMI, demographics</p> <p>ACS/Food Environment Atlas SDOH indicators</p> <p>NCHS Rural/urban</p>	<p>Fyfe-Johnson, A. L., Reid, M. M., Jiang, L., Chang, J. J., Huyser, K. R., Hiratsuka, V. Y., Johnson-Jennings, M. D., Conway, C. M., Goins, T. R., Sinclair, K. A., Steiner, J. F., Brega, A. G., Manson, S. M., & O’Connell, J. (2022). Social determinants of health and body mass index in American Indian/Alaska Native children. <i>Child Obesity</i>, 19(5), 341-352. https://doi.org/10.1089/chi.2022.0012</p>

PILOT INVESTIGATOR	DATA SOURCE(S)	POPULATION(S)	EXAMPLE MEASURES	PUBLICATION/REFERENCE
<p>Vanessa Hiratsuka (with Cheryl Conway, Amber Fyfe-Johnson, Kimberly Huyser, Michelle Johnson-Jennings)</p>	<p>IHS Improving Health Care Delivery Data Project (“IHS Data Project”); FY 2011</p> <p>US Census Data, American Community Survey (2010-2014)</p> <p>USDA Food Environment Atlas</p> <p>National Center for Health Statistics</p>	<p>AI/AN women-infant dyads</p>	<p>IHS Data Project Infant weight, mother demographics, mother health coverage, mother health status</p> <p>ACS/Food Environment Atlas SDOH measures</p> <p>NCHS Rural/urban</p>	<p>Hiratsuka, V. Y., Reid, M., Chang, J., Jiang, L., Brega, A. G., Fyfe-Johnson, A. L., Huyser, K. R., Johnson-Jennings, M., Conway, C., Steiner, J. F., Rockell, J., Dillard, D. A., Moore, K., Manson, S. M., & O’Connell, J. (2022). Associations between rurality, pre-pregnancy health status, and macrosomia in American Indian/Alaska Native populations. <i>Maternal and Child Health Journal</i>, 26(12), 2454-2465. https://doi.org/10.1007/s10995-022-03536-w</p>
<p>Michelle Johnson-Jennings (with Cheryl Conway, Amber Fyfe-Johnson, Vanessa Hiratsuka, Kimberly Huyser)</p>	<p>IHS Improving Health Care Delivery Data Project (“IHS Data Project”); FY 2013</p> <p>US Census Data, American Community Survey (2010-2014)</p> <p>USDA Food Environment Atlas</p> <p>National Center for Health Statistics</p>	<p>AI/AN adolescents aged 12–19 years who were active IHS users during fiscal year</p>	<p>IHS Data Project Obesity, demographics, health coverage, mental health and substance use disorders</p> <p>ACS/Food Environment Atlas SDOH measures</p> <p>NCHS Rural/urban</p>	<p>Johnson-Jennings, M. D., Reid, M., Jiang, L., Huyser, K. R., Brega, A. G., Steine, J. F., Manson, S. M., Chang, J., Fyfe-Johnson, A. L., Hiratsuka, V., Conway, C., & O’Connell, J. (2023). American Indian Alaska Native (AIAN) adolescents and obesity: the influence of social determinants of health, mental health, and substance use. <i>International Journal of Obesity</i>, 47(4), 297-305. https://doi.org/10.1038/s41366-022-01236-7</p>

OTHER LARGE-SCALE DATA SETS

DATA SOURCE(S)	DESCRIPTION	PUBLICATION/REFERENCE	WEBSITE
American Community Survey (ACS)	ACS is an annual demographics survey program conducted by the U.S. Census Bureau that asks about ancestry, US citizenship status, educational attainment, income, language proficiency, migration, disability, employment, and housing characteristics	See the ACS website for a list of publications and reports	https://www.census.gov/programs-surveys/acs
Behavioral Risk Factor Surveillance System (BRFSS)	This annual survey collects state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services and collects data in all 50 states, the District of Columbia, and three U.S. territories	See the BRFSS website for a list of publications and reports	https://www.cdc.gov/brfss/index.html
California Health Interview Survey (CHIS)	More than 20,000 California households — including adults, adolescents, and children — are interviewed each year	See the CHIS website for a list of publications	https://healthpolicy.ucla.edu/our-work/california-health-interview-survey-chis/access-chis-data
Medical Expenditure Panel Survey (MEPS)	MEPS is a set of large-scale surveys of families and individuals, their medical providers, and employers across the US and is the most complete source of data on the cost and use of health care and health insurance coverage	See the MEPS website for a list of publications	https://meps.ahrq.gov/
Medicare data/Medicaid data	This site gives you direct access to public data released by the Centers for Medicare & Medicaid Services (CMS)	N/A	https://data.cms.gov/

DATA SOURCE(S)	DESCRIPTION	PUBLICATION/REFERENCE	WEBSITE
National Longitudinal Study of Adolescent to Adult Health (Add Health)	Add Health is a longitudinal study of a nationally representative sample of over 20,000 adolescents who were in grades 7-12 during the 1994-95 school year, and have been followed for five waves to date, most recently in 2016-18	See the Add Health website for a list of publications	https://addhealth.cpc.unc.edu/
Pregnancy Risk Assessment Monitoring System (PRAMS)	PRAMS collects jurisdiction-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy	See the PRAMS website for a list of publications	https://www.cdc.gov/prams/index.htm
SEARCH for Diabetes in Youth Study	National study of youth aged 0-19 years with a physician diagnosis of type 1 or type 2 diabetes at five centers in the USA between 2002 and 2018	See the SEARCH for Diabetes in Youth Study website for a list of publications	Anna Bellatorre, PhD (Anna.Bellatorre@cuanschutz.edu)
United States Renal Data System	People with end-stage renal disease or chronic kidney disease	See the USRDS website for a list of publications	https://www.niddk.nih.gov/about-niddk/strategic-plans-reports/usrds

DATABASES

DATABASE	DESCRIPTION	EXAMPLES	WEBSITE
Health Research Databases	The Health Research Databases lists and describes many other databases that can be used for research. The website has a list of several public-use databases that can be used in research studies. Most of these resources are freely available online. Some will require a study proposal and/or data use agreement be submitted and evaluated.	The database provides the following for each data source: organization source, website, data description, vintage/release frequency, observational unit, collection methodology, where the data is available at, user guide/data dictionary, cost, proposal/application required for use, and if a DUA is required to use the data.	https://cu-anschutz-dos-corp.github.io/researchDatabases/