AIDC@P

FIRST ANNIVERSARY ACCOMPLISHMENTS

At a glance

SINCE AUG. 2015, MEMBERSHIP HAS INCREASED

215%

82 Total
MEMBERS REPRESENTING

12 TRIBAL NATIONS

&

10 SECTORS OF COMMUNITY, STATE, TRIBAL & FEDERAL ENTITIES

Combined Years of Experience

DATA (640 YEARS)

AMERICAN INDIAN DATA (360 YEARS)

0   100   200   300   400   500   600   700

Data
Statistics
Collection
Advancement
Community
Planning
Risk
Health
Alliance
Tribal
Biostatistics
Evaluation
Research
Experience
Service
Wellness
Tribes
Prevention
Care
Epidemiology
Public
Development
Indian

As these descriptive data suggest, we are a growing community network which is gaining momentum in increasing knowledge and access to relevant American Indian information, research, and data sources, in fostering research collaborations, and in a building of community that will ultimately promote data-informed decisions to positively impact American Indian health and wellness.

At **AIDCOP** *We learned...*

1) **The VITAL** importance of consulting with tribal nations and partners prior to data use and dissemination.

2) **PUBLICALLY AVAILABLE** American Indian data sources exist and contain data on:

- Birth, infants, toddlers, adolescents, and adults
- Health behaviors
- Disease rates - diabetes, asthma, COPD, hypertension, etc.
- Behavioral health
- Mortality and causes of death
- Child welfare, foster care, maltreatment, and adoption

3) **PUBLICLY AVAILABLE DATA SOURCES AND REPORTS** *see table 1 on page 3*

4) **SPECIFIC CHALLENGES** exist with American Indian data that are not well known or recognized to outside entities, such as poor interfacing and linking with state surveillance systems, inaccuracies in racial coding, different requirements for IRB applications, and lack of respect for tribal sovereignty.

Table 1

Publicly Available Data Sources and Reports	Presenters
1. **OK2SHARE** (http://www.health.state.ok.us/ok2share/) Oklahoma Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Birth defects and cancer registries, and hospital discharge	Dr. Derek Pate DerekP@health.ok.gov
2. **Pregnancy Risk Assessment Monitoring System (PRAMS) and PRAMStat** (https://www.cdc.gov/prams/ and http://www.cdc.gov/prams/pramstat/) A surveillance administered by the CDC that collects state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. Currently covers about 83% of all U.S. births.	Ms. Binitha Kunnel BinithaK@health.ok.gov
3. **The Oklahoma Toddler Survey (TOTS)** (www.ok.gov/health/Community_&_Family_Health/Maternal_and_ Child_Health_Service/Data_and_Evaluation/The_Oklahoma_Toddler_Survey_(TOTS)/) A two-year follow up survey to theOklahoma Pregnancy Risk Assessment Monitoring System (PRAMS) respondents, collects data on health care and insurance, illness and injury, childcare, safety, breastfeeding, secondhand smoke exposure, and family structure.	
4. **First and Fifth Grade Surveys** (www.ok.gov/health/Community_&_Family_Health/Maternal_and_Child_ Health_Service/Data_and_Evaluation/First_Grade_Health_Survey/index.html) Child's health status, including general health issues, injuries, and access to and utilization of insurance or governmental programs.	
5. **CDC Wonder** (http://wonder.cdc.gov/) Mortality, cancer incidence, HIV and AIDS, tuberculosis, vaccinations, natality (births), census data and many other topics.	
6. **Oklahoma Violent Death Reporting System (OKVDRS)** (https://www.ok.gov/health/Protective_Health/Injury_Prevention_Service/Oklahoma_Violent_Death_Reporting_System/index.html) Homicides, suicides, deaths due to unintentional firearm injury, legal intervention, terrorism, and deaths of undetermined manner/intent.	Brandi Woods-Littlejohn BrandiW@health.ok.gov
7. **National Violent Death Reporting System (NVDRS)** (http://www.cdc.gov/ViolencePrevention/NVDRS/index. html and http://www.cdc.gov/injury/wisqars/nvdrs.html) All types of violent deaths, including homicides and suicides in all settings and for all age groups for participating states, including Oklahoma from 2004-2013. Also have mental health problems; recent problems with a job, finances, or relationships, physical health problems, and information about circumstances of death data.	
8. **Oklahoma Dept. of Mental Health and Substance Abuse Services Behavioral Health Data Query System** (https://www.ok.gov/odmhsas/Additional_Information/Statistics_and_Data/) Number of Oklahomans served by the department's programs and admissions by drug of choice. The information can be divided by geographic and demographic parameters, as well as produce charts to visual the data.	Tracy Leeper tleeper@odmhsas.org Dr. Mark Reynolds MAReynolds@odmhsas. org
9. **Substance Abuse and Mental Health Services Administration: National Survey on Drug Use and Health** (http://www.samhsa.gov/data/population-data-nsduh) National and state-level data on the use of tobacco, alcohol, illicit drugs (including non-medical use of prescription drugs) and mental health in the United States	
10. **Oklahoma Dept. of Human Services Child Abuse and Neglect Report** (http://www.okdhs.org) Child abuse and neglect, investigations or assessments conducted and investigation confirmations.	Connie Schlittler – resigned from the Oklahoma Dept. of Human Services. New contact: Dr. Shannon Rios Shannon.Rios@okdhs.org
11. **Boston University: U.S. and Oklahoma Child Welfare/Foster Care Data** (http://www.bu.edu/ssw/usfostercare/) State level child welfare and foster care data	
12. **The Center for State Child Welfare Data** (https://fcda.chapinhall.org/) Analytic infrastructure and decision support to help child welfare agencies improve outcomes from the inside out.	
13. **Administration for Children and Families: Child Maltreatment** (http://www.acf.hhs.gov/cb/research-data-technology/statistics-research/child-maltreatment) National data about child abuse and neglect known to child protective services agencies in the United States since 1995.	
14. **Administration for Children and Families: Race/Ethnicity of Public Agency Children Adopted Report** (http://www.acf.hhs.gov/cb/resource/race-2014) State-specific data from fiscal year 2014 about the race and ethnicity of children who were adopted through public agencies	
15. **KIDS COUNT** (http://oica.org/kid-count-data-center/) Demographics, economic-well-being, education, family and community, health, and safety and risky behaviors	Lani Habrock lhabrock@oica.org
16. **Oklahoma Tobacco Helpline Report** Commercial tobacco user registrants' aggregate demographics, commercial tobacco usage and history, characteristics, tribal affiliation, etc. Access to raw or individual-level data is restricted.	Dr. Laura Beebe Laura-Beebe@ouhsc.edu

Members Experience At AIDCoP

"AIDCoP has had the biggest impact for Cherokee Nation in the new partnerships we have created that can only be accomplished face-to-face in an open environment. I find it to be a safe place to ask questions, seek assistance, and to share our successes and failures. I have been truly amazed at the scope of activities occurring in Oklahoma in regards to Native American health data as well as the depth of the knowledge and skills of people from across disciplines. Specifically, we have enlisted assistance from our academic partners in complex data analyses of our tobacco survey data and we are partnering with several groups in research projects that align perfectly with Cherokee Nation Health Services Strategic Plan".
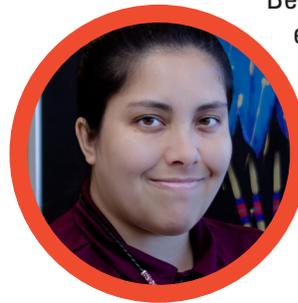
– Dr. David Gahn

"For me, AIDCoP serves as a place to see people I work with virtually on a regular basis in person, and discuss data issues of interest to all parties. Sharing of resources is easier through the AIDCoP mechanism and we are able to be a part of something bigger than just an occasional two-way email conversation. AIDCoP meetings provide a forum for sharing in person with our data partners on a regular basis".

– Ms. Julie Erb-Alvarez

"There are long standing issues with American Indian data in public health surveillance and we have come to accept the deficits. AIDCoP gives us an avenue to explore innovation to improve public health surveillance as a whole."

– Dr. Malinda Douglas

"Being a part of AIDCoP has been an eye-opening experience. It has been inspiring to know that we face similar issues, regardless if we are smaller tribes or larger tribes with more infrastructure for research, or those of us who are just building capacity for research. I'm grateful for the opportunity to share, learn, and network together in a way that hasn't been done before. As we strive to improve wellness outcomes for all people in Oklahoma, we can do so much more together."

– Ms. Melody Redbird-Post

We learn to address challenges while strive to take American Indian data to the next level in sensitive, respectful, and meaningful ways!

Happy first anniversary, AIDCoP!