

Update on the Environmental influences on Child Health Outcomes Program (ECHO)

Learning to ‘Walk Softly and Listen Carefully’*

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September 15, 2017

*NCAI Policy Research Center & MSU (2012); <http://www.ncai.org/>



ECHO Environmental influences
on Child Health Outcomes

NIH National Institutes of Health
Environmental influences on Child Health Outcomes (ECHO)

Three Things to Remember

- The ECHO program is committed to **listening** to Tribal nation concerns.
- ECHO is a new program and based on what we **hear**, we can try NEW ways of doing things.
- We want Tribal nations and communities to **benefit** from the ECHO program.



ECHO Mission

Enhance the health of children
for generations to come



ECHO

ECHO Overall Scientific Goal

Answer crucial questions about effects
of
broad range of early environmental exposures
on
child health and development



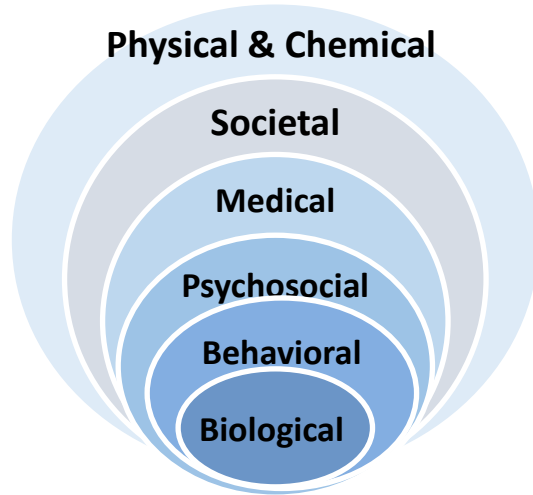
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Exposures from Society to Biology

Macro



Micro



From conception to age 5



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Focus on High-Impact Health Conditions

PRE-, PERI-
AND POSTNATAL



UPPER AND
LOWER AIRWAY



OBESITY



NEURO-
DEVELOPMENT



POSITIVE CHILD HEALTH



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Meet Scientific Needs and Inform Programs, Practice, Policy

- **Long-term studies (observational)**
 - Ask solution-oriented questions
- **Clinical Trials Network (intervention)**
 - Children underrepresented in clinical trials
 - Rural, medically underserved
- **Both**
 - Answer broad scientific questions
 - Apply to specific communities

We All View the World through Cultural Lens



Listening in Alaska – June 2017



Alaska Native Medical Center



National Tribal Public Health Summit



ECHO



Listening in Navajo Nation- August 2017



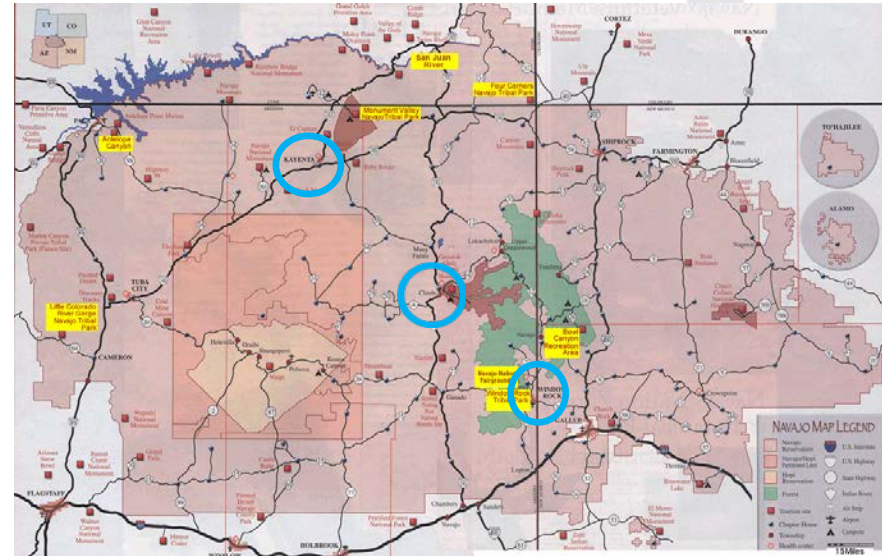


Listening in Navajo Nation- August 2017


Navajo Nation Human Research Review Board

§ 3253. Policy


- A. All persons within the territorial jurisdiction of the Navajo Nation are free from unreasonable harmful, intrusive, ill-conceived or otherwise offensive research and investigation procedures.
- B. Research conducted is beneficial, community-based, and consistent with Navajo Nation priority and concerns.
- C. Research information and data generated by and about Navajo individuals, communities, culture represent inalienable intellectual properties of the Navajo people and over which the Navajo Nation will provide oversight.



Listening in Albuquerque – August 2017



TRIBAL DATA SHARING & GENETICS
Policy Development Workshop



August 31 - September 1, 2017
UNM Comprehensive Cancer Center
1201 Camino de Salud, NE - ABQ, NM 87131
sites.google.com/view/UNMCEHP17
livestream available beginning August 31 at
<http://206.192.150.42>
Contact: C.J. Laselute | 505.272.7407 | claselute@salud.unm.edu

This workshop will bring together tribal policy and spiritual leaders, health researchers, and community members to discuss and understand the benefits and risks for Native American populations from participating in genetic research studies. Through open dialogue, the goal will be to develop policy recommendations for genetic studies and sharing of research data.

artwork by Mistery Quinsawi, Artist-in-Residence, UNM Center for Native Environmental Health Equity Research

- Research should benefit Tribal Nations
- Concept of reciprocity
- Informed consent process for both individuals and Tribal nations
- Oversight of any secondary analysis of data
- Tribal nations need to be asked about what scientific research is important to them



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What do you hear when you listen? What is lost in translation?

Diné

Ke'yah

English

Land



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We Must Acknowledge History

“Theft has been the overriding experience of native people in North America since the time of first contact...”*



Theft of: land, sovereignty, family members, language, culture, religion, knowledge, religious and cultural articles, native symbols, ancestral bones, and more...

*Bowekaty MB & Davis DS. IRB: Ethics and Human Research 25(4):12-15, 2003.



ECHO

Taking the Time to Build Trust

Respect

Culture

Equity



Navajo Birth Cohort Study

Dr. J. Lewis, PI; and Collaborators M-G. Begay (Navajo) & Dr. D. Begay (Navajo)



Photo Credit: Teddy Nez, Southwest Research and Information Center, UNM

Uranium and other metals

Examines relationships of exposure to metals in pregnancy with

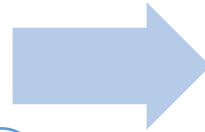
- Brain development
- Excess weight gain

And how development of the immune system explains the relationships

Navajo Nation is Sharing Data Already

Navajo Birth Cohort Study

- Dr. J Lewis, PI, UNM
- Collaborators:
 - M-G Begay, Navajo Nation DOH (Navajo) &
 - Dr. D. Begay, UNM (Navajo)

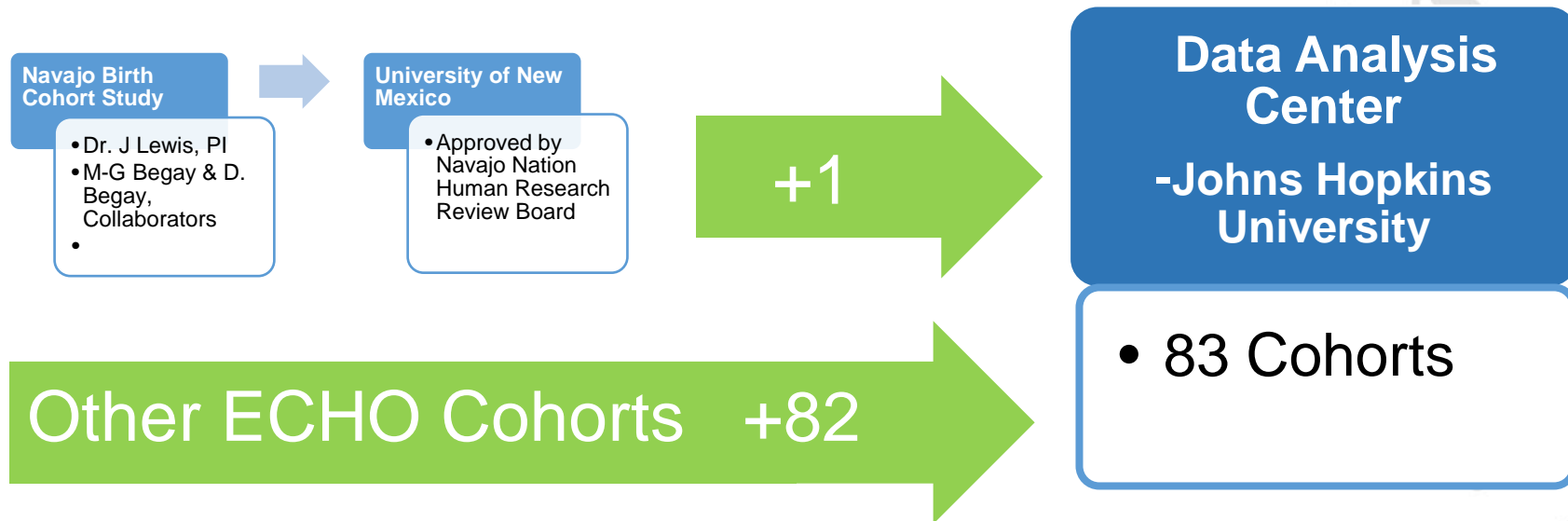


University of New Mexico

- Approved by Navajo Nation Human Research Review Board



How can we safely share Navajo Nation data with the ECHO-Wide Cohort?



Why do we want to share data?



Data Analysis Center

- Increases the ability to address important research questions that could benefit Tribal Nations
- Multiple factors and how they interact
- Same exposures and different outcomes

The 'Working' Plan for ECHO Data Sharing

Controlled Access –
Scientific Purpose
reviewed & approved
by ECHO Steering
Committee

ECHO-wide
central repository



Public Use Data Set.
Must register to use.
Do not need ECHO SC
Approval

ECHO De - Identified
Resource

Data Sharing
VS.
Data Use

We Need to Explicitly Address Concerns

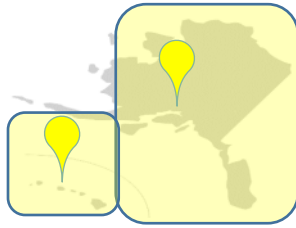
- Risks versus benefits of sharing
- What data tribal nations able to share
- Self-identified ~ tribal-identified affiliation
- Conditions of use
- Privacy, safety, security
- Duration of storage and use
- Oversight of data analyses
- Returning data and sharing findings
- Intellectual property rights
- Publications, manuscripts, reporting



IDeA States Pediatric Clinical Trials Network 5 states with high % indigenous populations

Future Opportunities?

- American Indian
- Alaskan Native
- Native Hawaiian



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Weaving a Tapestry



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A program supported by the NIH

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