

NIH Tribal Consultation Advisory Committee

ECHO

Environmental influences on Child Health Outcomes

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10 March 2017

Asking TCAC Advice

- ECHO committed to consultation with Tribal Nations
- Collaborate with our AI/AN partners
 - Attend to cultural and historical issues
 - Research that both
 - Serves AI/AN communities directly
 - Enhances the ECHO commons for consortia-wide research

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 - Sharing data and biospecimens
 - » Work in progress

Question—General

- Best ways for...
 - NIH ECHO Program Office and
 - Investigators...to build relationships with Tribal Nations and collaborate to address concerns?

Questions—Specific

Sharing data and biospecimens—work in progress

- What data and specimens tribal communities able to share
 - With whom
- Self-identified↔tribal-identified affiliation
- Conditions of use by
 - ECHO investigators
 - Wider scientific community
- Privacy, safety, security
- Duration of storage/use
 - Final disposition, ownership

Questions—Specific

Sharing data and biospecimens—work in progress

- What data and specimens tribal communities able to share
- Self-identified↔tribal-identified affiliation
- Conditions of use
- Privacy, safety, security
- Duration of storage/use
- **Genetics**
 - Same principles? Special case?

Today

- ECHO
 - Goals
 - What are we doing
 - How we are doing it
- Return to the questions

ECHO Mission

Enhance the health of children for
generations to come



ECHO

A Nationwide Program



Guiding Principles

- **Teamwork**

Working well together

- **Impact**

Research that has an impact on health

- **Responsibility**

Scientifically & ethically sound research

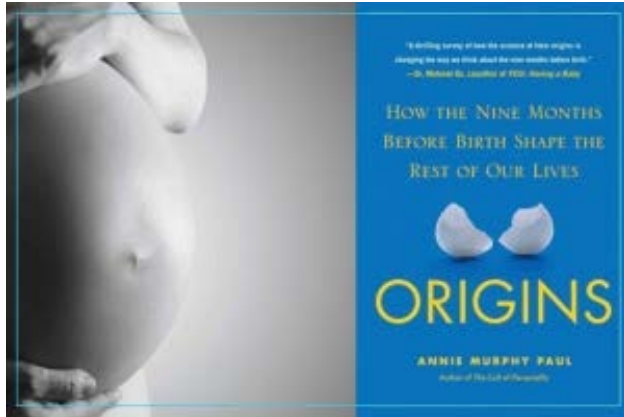
- **Value**

Good stewardship, return on investment

ECHO Overall Scientific Goal

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

A good start to life...



Joseph Tart/EHP

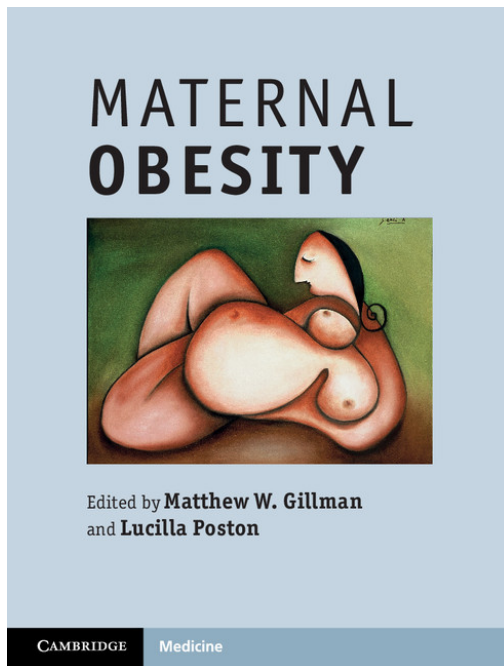


...can last a lifetime...

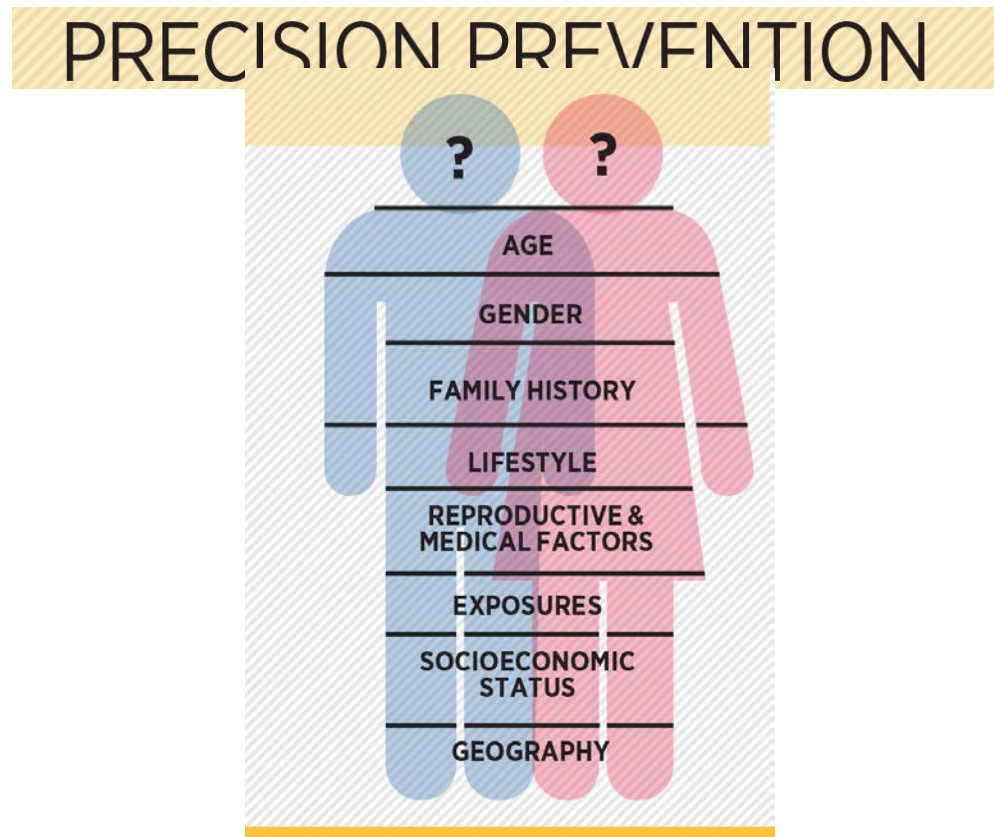


...and over many generations

To ensure a good start, need to understand potential risks...



To ensure a good start, need to understand potential risks...
...and to whom they apply...



... then take action

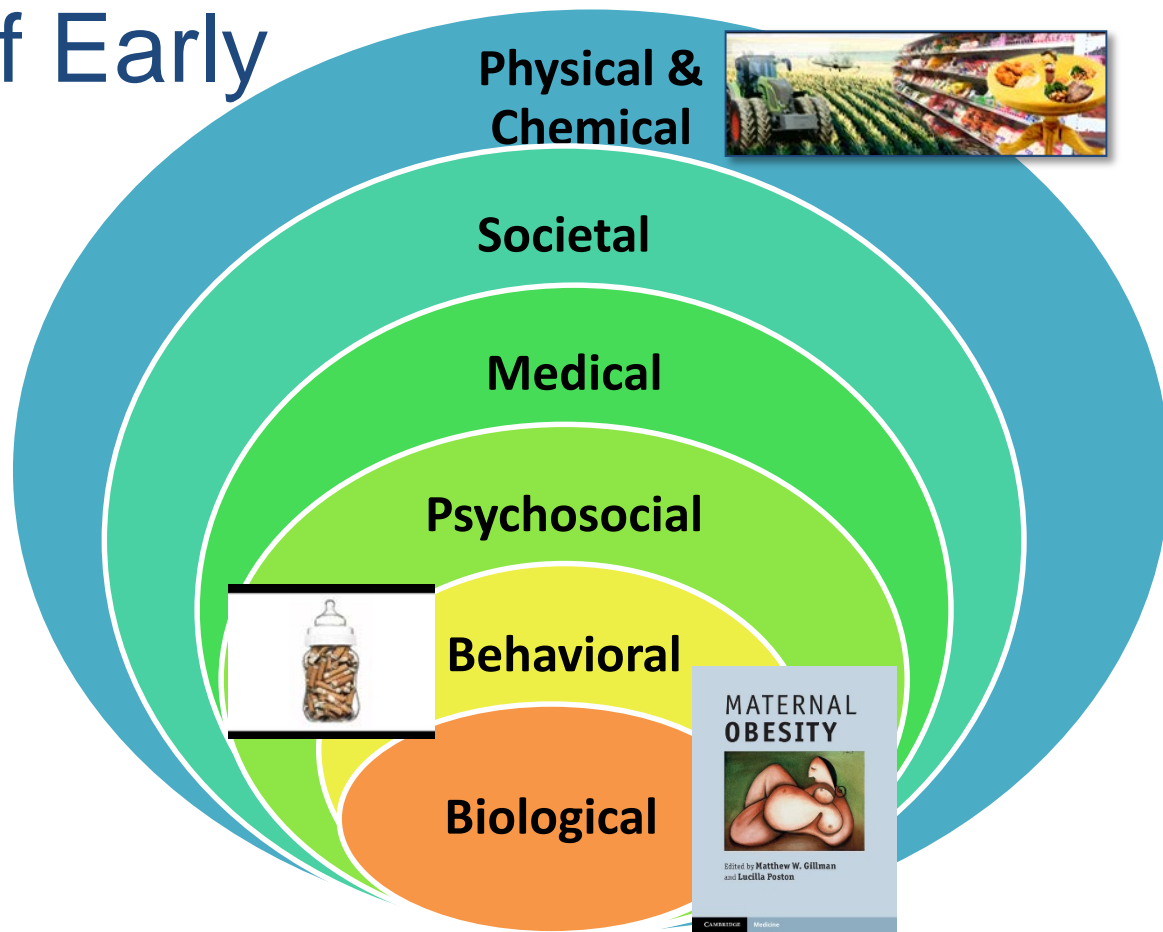


CLINICAL TRIALS



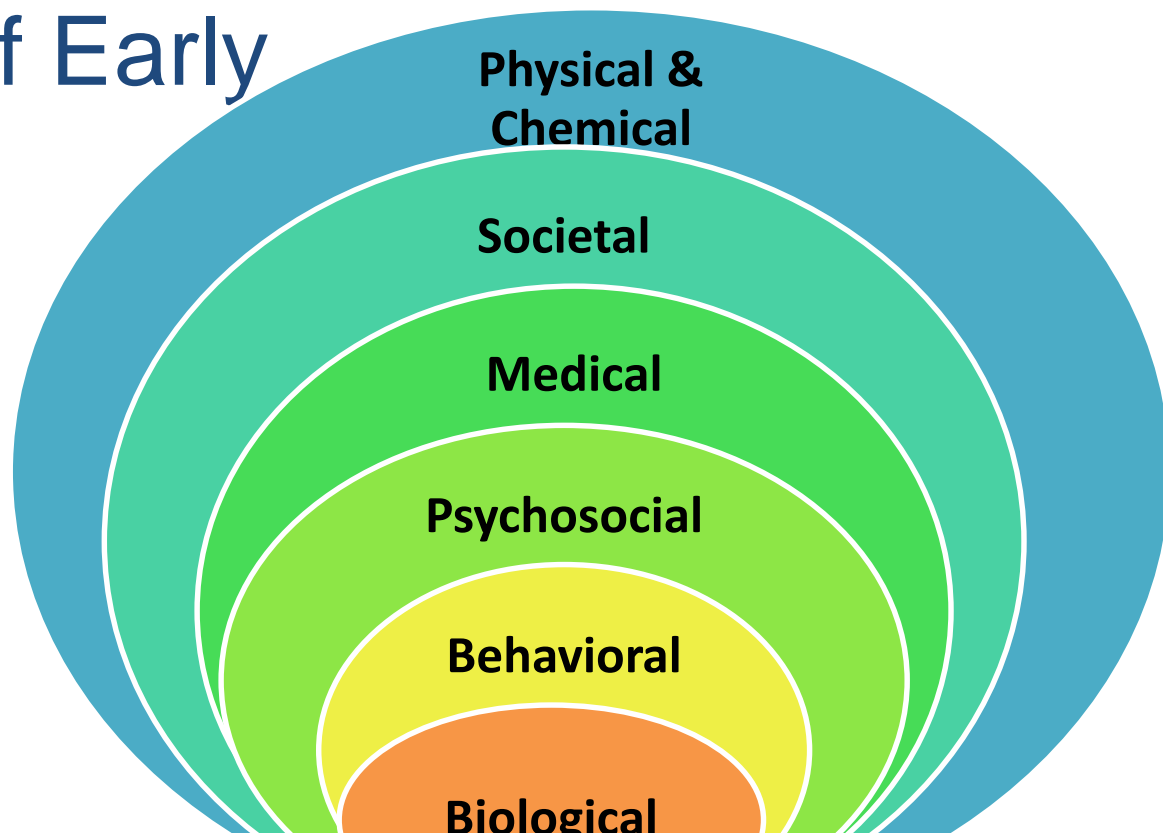
Broad Range of Early Environmental Exposures

From society to biology



Broad Range of Early Environmental Exposures

From society to biology



- *Exposures from conception to age 5 years*
- *Health outcomes throughout childhood and adolescence*



Health Outcomes

Focus on High-Impact Pediatric Conditions

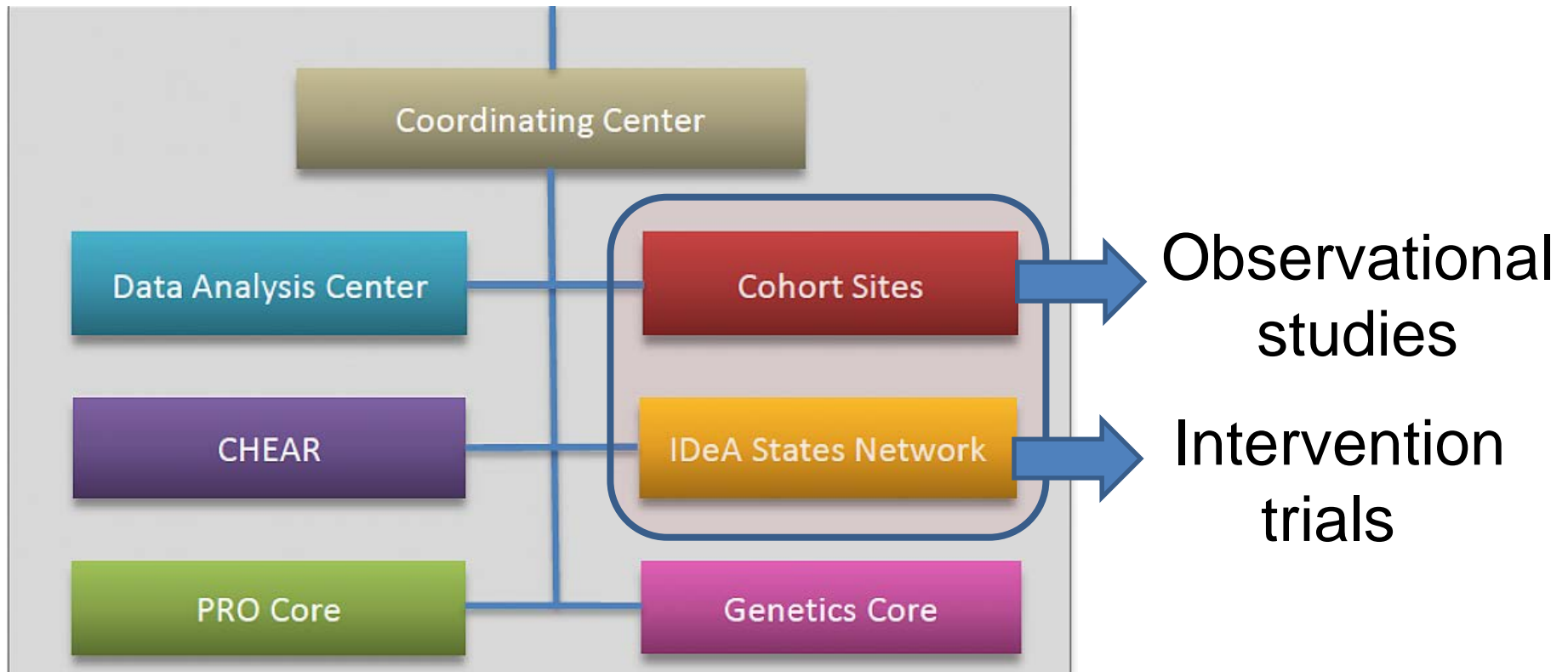
1. Pre/peri/postnatal outcomes
2. Obesity
3. Upper & lower airway
4. Neurodevelopment
5. Positive health

Health Outcomes

Focus on High-Impact Pediatric Conditions

1. Pre/peri/postnatal outcomes
2. Obesity
3. Upper & lower airway
4. Neurodevelopment
5. **Positive health**
 - Well-being
 - Life satisfaction
 - Positive affect
 - Meaning and purpose
 - Sleep duration and quality

ECHO Components



Meet Scientific Needs and Inform Programs, Practice, Policy

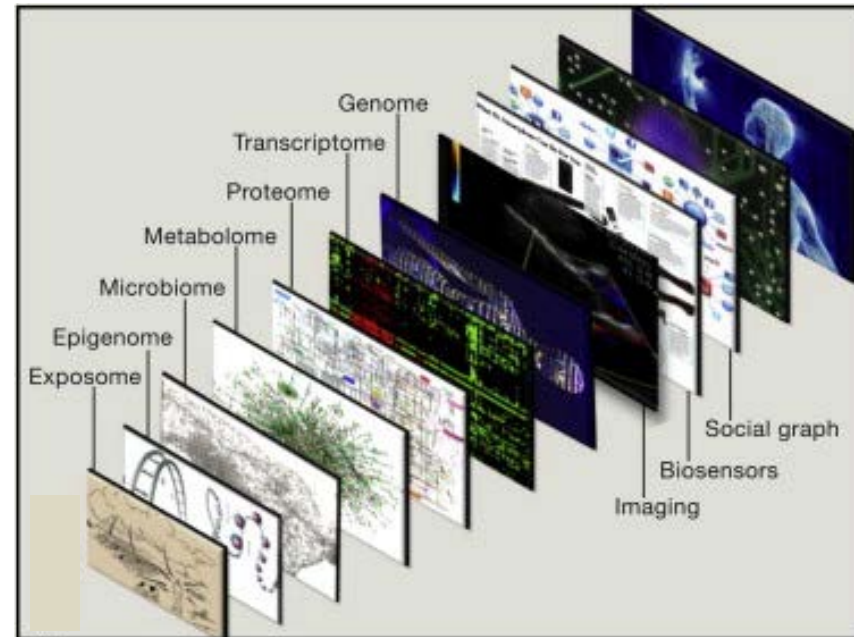
- Observational studies
 - Ask solution-oriented questions
 - “So what” questions that have impact
- Intervention trials
 - Children underrepresented in clinical trials
 - Especially hard-to-reach populations
 - Rural, medically underserved
- Both
 - Answer broad scientific questions
 - Apply to specific communities

Major Observational Objective: Create The ECHO-wide Cohort

- Start with multiple existing cohorts (longitudinal studies) of moms & kids
 - Increase likelihood of early successes
 - Continue to recruit new & follow existing participants
- Combine into single *data platform* to conduct solution-oriented observational research
 - Harmonized existing measures
 - Standardized new measures
- To be used
 - By ECHO investigators, then
 - As a national research resource

The ECHO-wide Cohort

Many people, many layers of data,
many stages of life course



35 awards
74 PIs, 84 cohorts

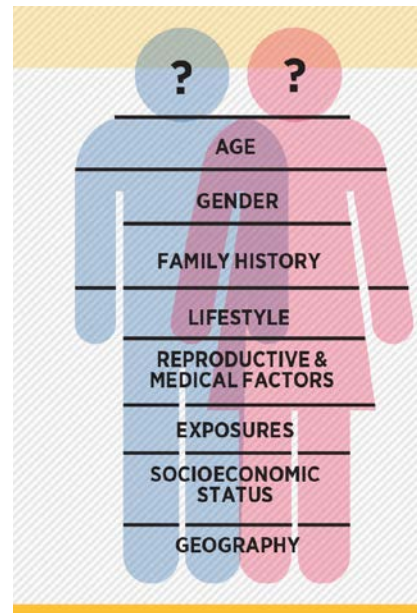
-Majority started prenatally-



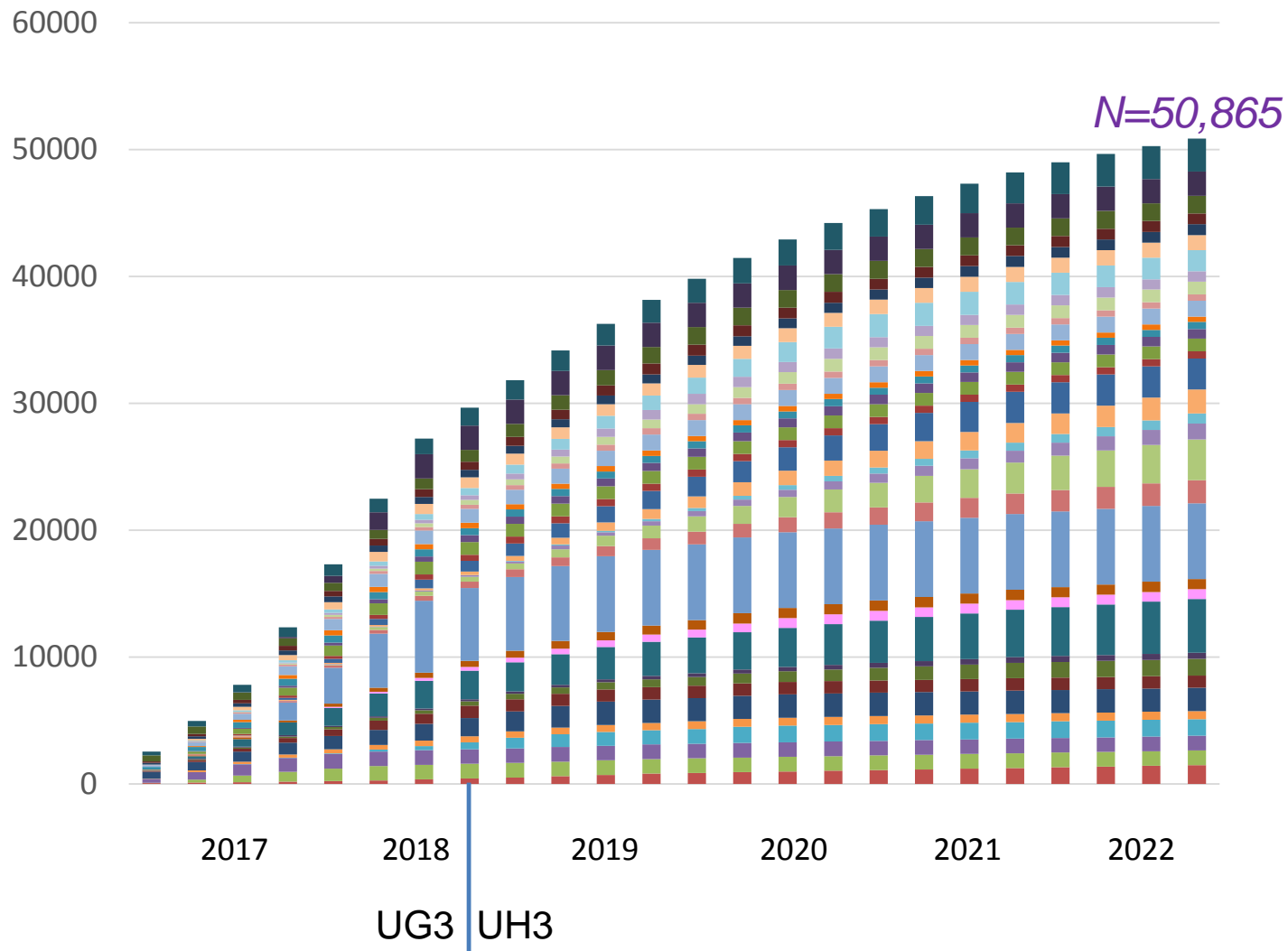
Cohort Prime Awardees
Cohort Sub-Awardees

The ECHO-wide Cohort

- Goal >50,000 children
 - Less common exposures & outcomes
 - To whom do results apply?



On our Way to 50,000 ECHO Children



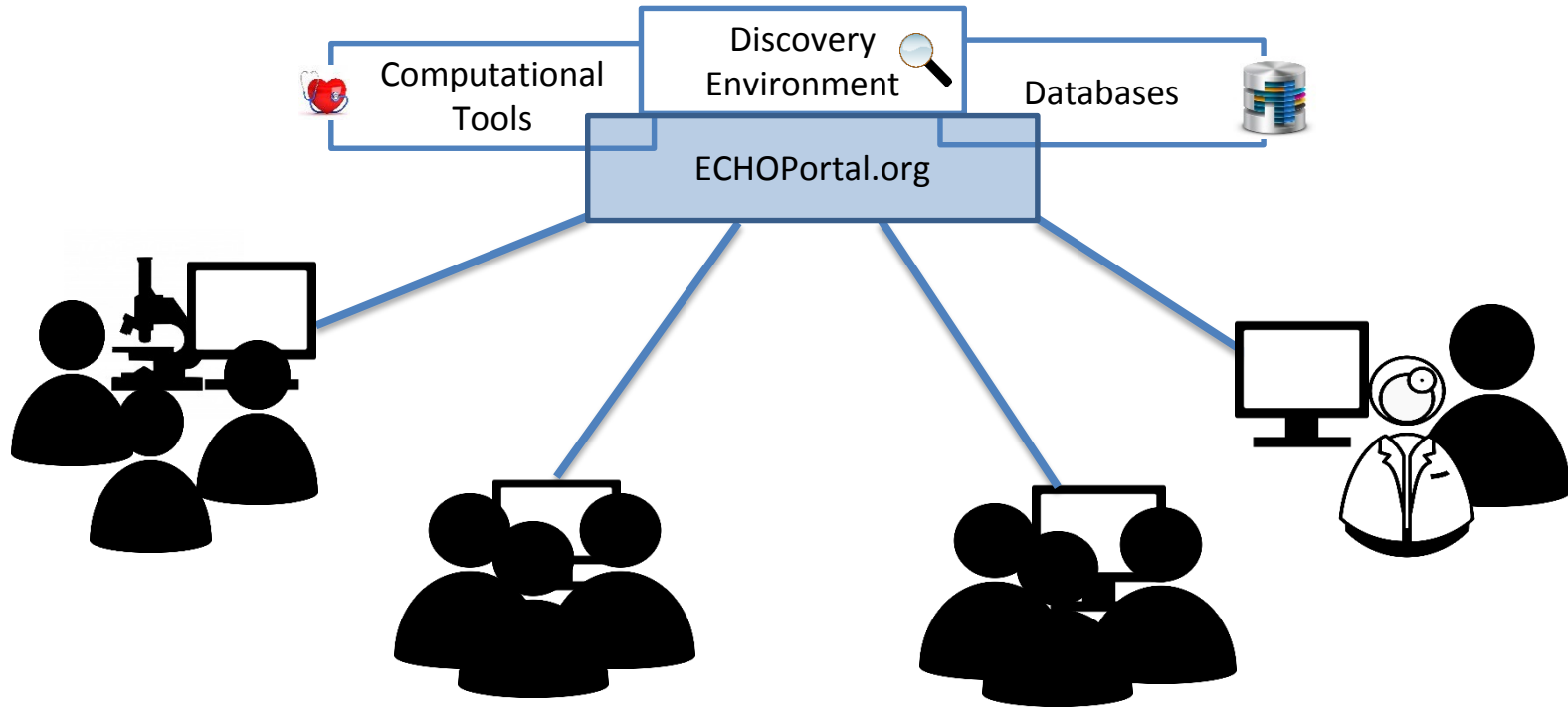
Data Safety & Security



Data Analysis Center

ECHOPortal.org

Hybrid cloud environment for data capture, storage, & analysis, and to foster collaboration



Researchers have controlled access—only to parts relevant for their specific work

- 2-factor authentication—prove identity twice before logging in

ECHOPortal.org

Purpose-built security and functionality

- Security controls
 - “FISMA Moderate”: severe risk if information compromised
- Data
 - Encrypted
 - Stay in restricted data vault
 - Controlled access
 - Particular researchers for particular analyses
- Tracking of all user actions
- Independent security audit, continuous monitoring

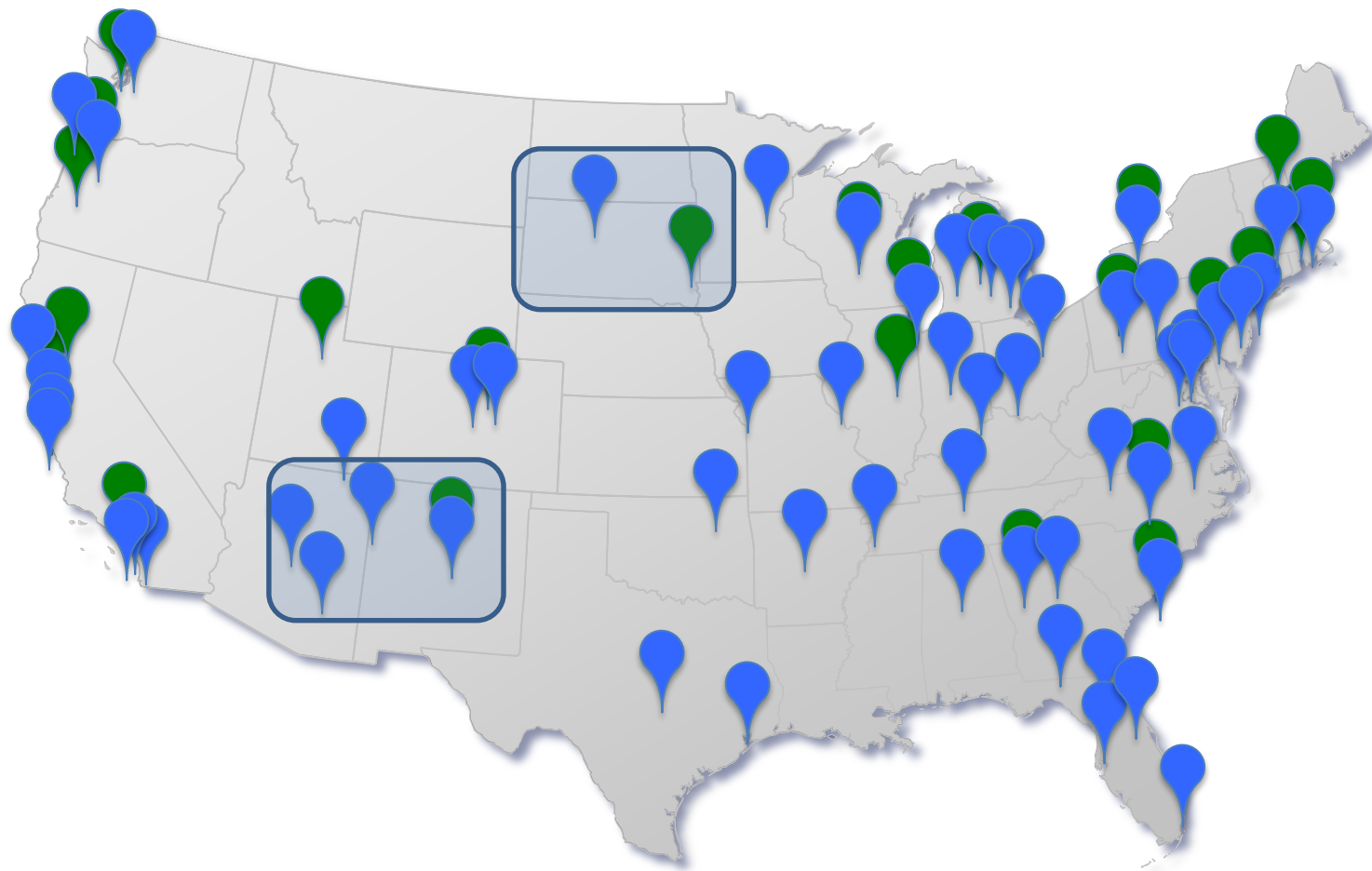
Diversity in geography, age, sex, social class, race/ethnicity

Asian	Black or Af-Am	AI/AN	White	Multi
5%	17%	3%	66%	10%

Hispanic
26%

*Preliminary
Data*

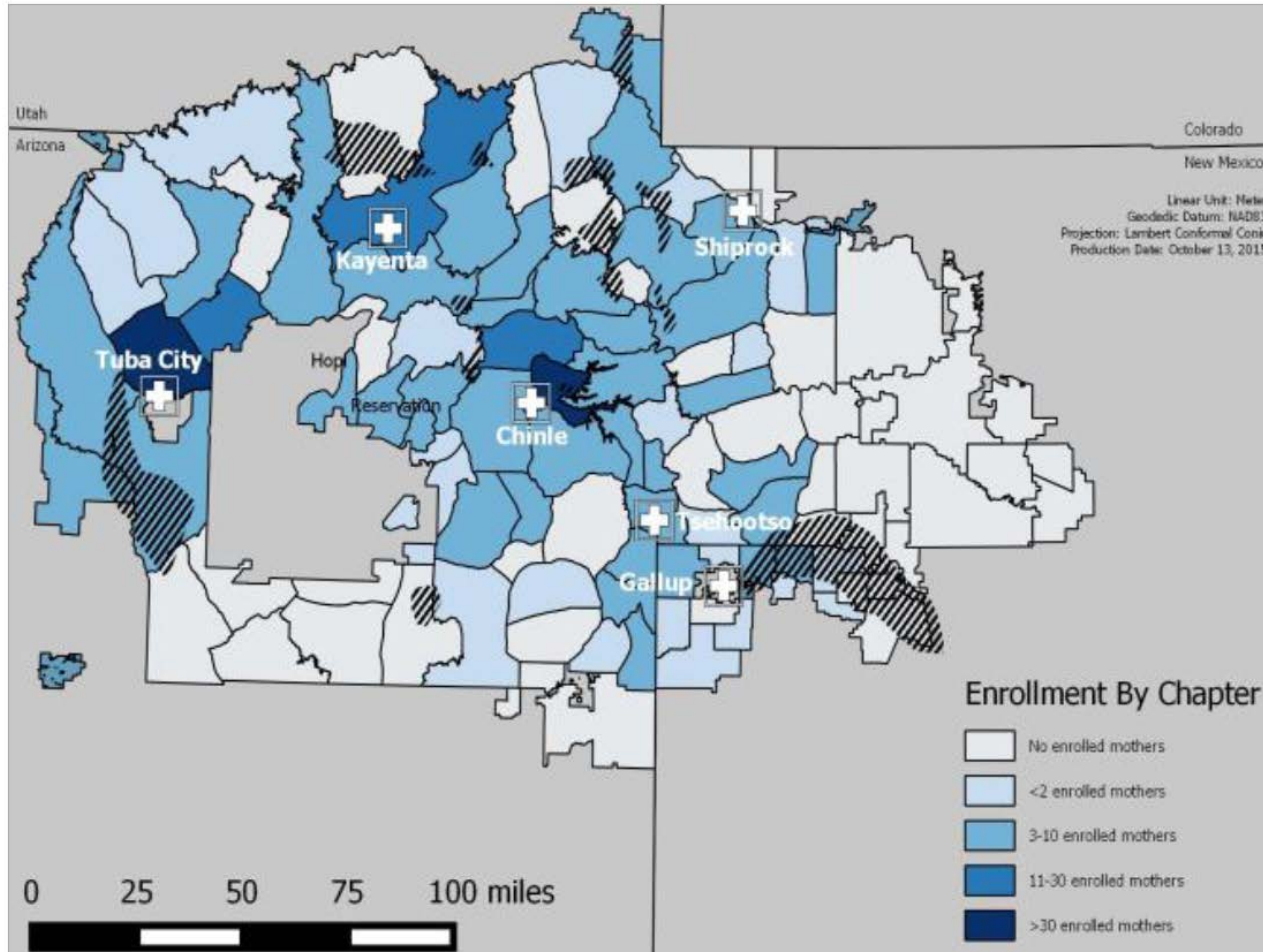
2 Cohorts Account for the Majority of AI/AN Participants



Cohort Prime Awardees
Cohort Sub-Awardees

Navajo Birth Cohort Study

J. Lewis, PI; M-G. Begay & D. Begay, Collaborators



~400 families followed from prenatal period through 4 years

Navajo Birth Cohort Study



Uranium and other metals, often from abandoned mines

Navajo Birth Cohort Study



Uranium and other metals, often from abandoned mines

Examine relationships of exposure to metals in pregnancy with

- Brain development
- Excess weight gain

And how development of the immune system explains the relationships

Navajo Birth Cohort Study

- Addresses concern of Navajo Nation
 - Individual cohort analysis, N ~400
 - Could spur further mitigation activities

Navajo Birth Cohort Study

- Addresses concern of Navajo Nation
 - Individual cohort analysis, N ~400
 - Could spur further mitigation activities
- Contributes to broader understanding of metals exposure and important child health outcomes
 - ECHO-wide analyses, N ~ 10,000s
 - With large sample of children, see how relationships vary by
 - Geography
 - Race/ethnicity
 - Socioeconomic position
 - Child sex
 - [Mother's or child's genes?]
 - Informs policies with impact on many populations

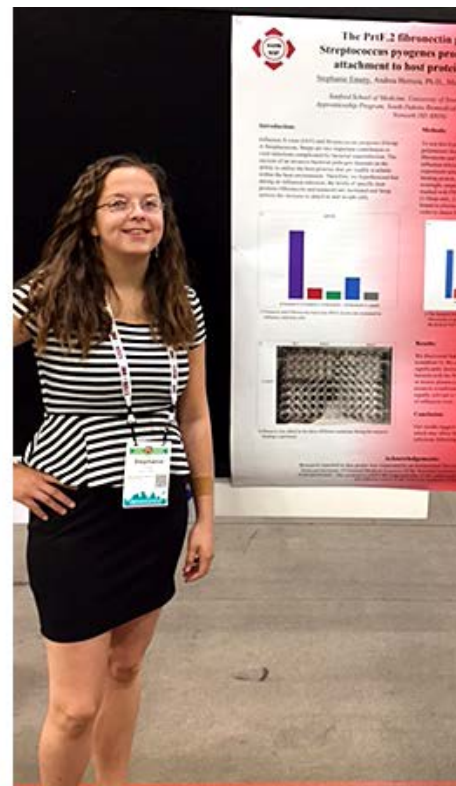
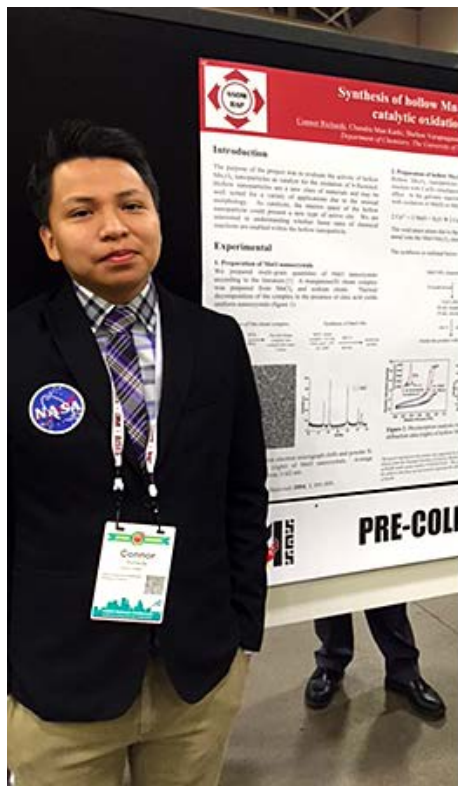
IDeA States Pediatric Clinical Trials Network

Overarching Goals

- Provide access to state-of-the-art clinical trials
 - Medically underserved and rural populations
- Build national pediatric research capacity
 - To conduct clinical trials
 - professional development for faculty
 - infrastructure and team support
- In formative stages...

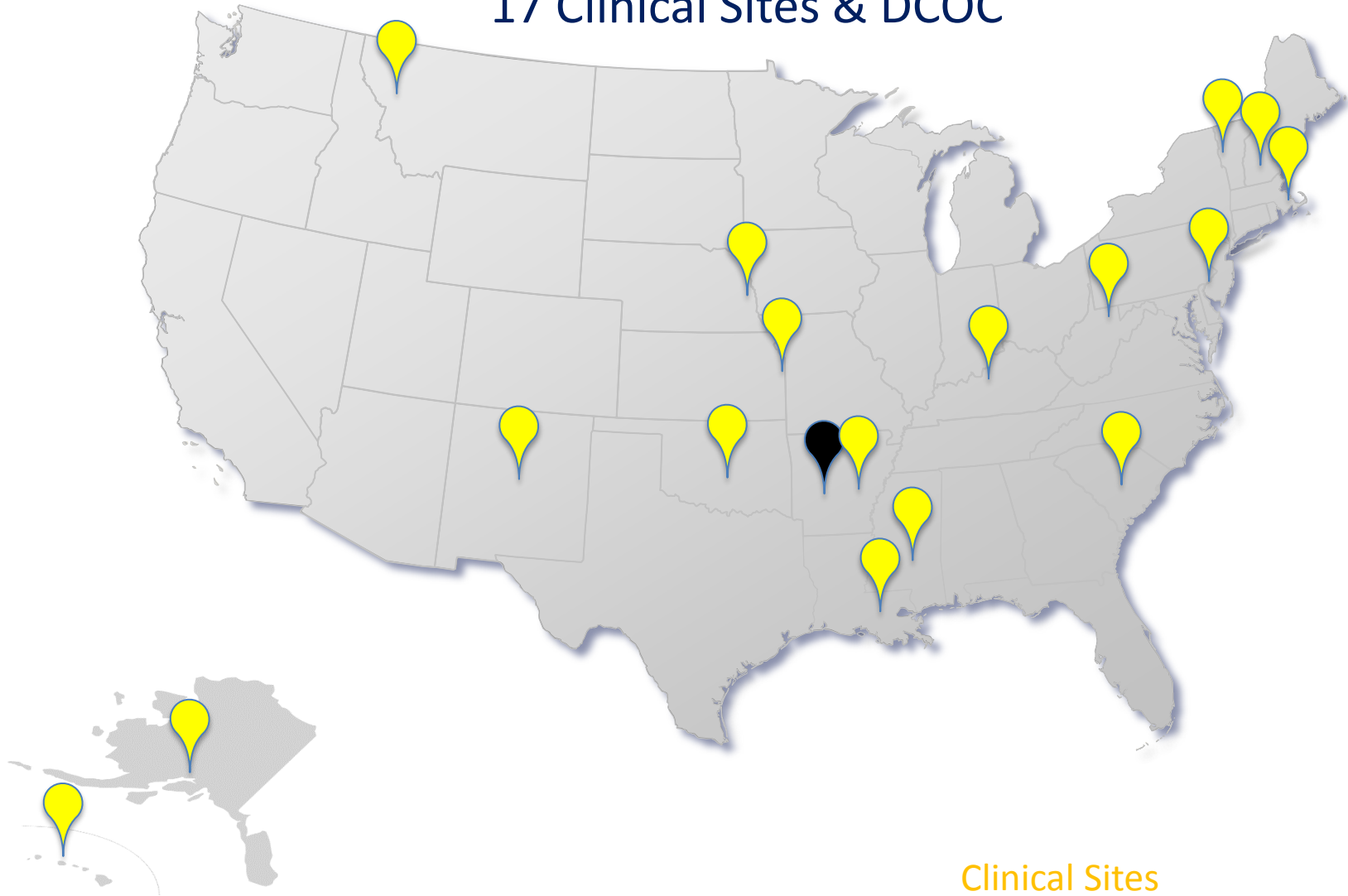
IDeA States Pediatric Clinical Trials Network Capacity Building

- Mentoring emerging scientists
- Training and support for staff



IDeA States Pediatric Clinical Trials Network

17 Clinical Sites & DCOC

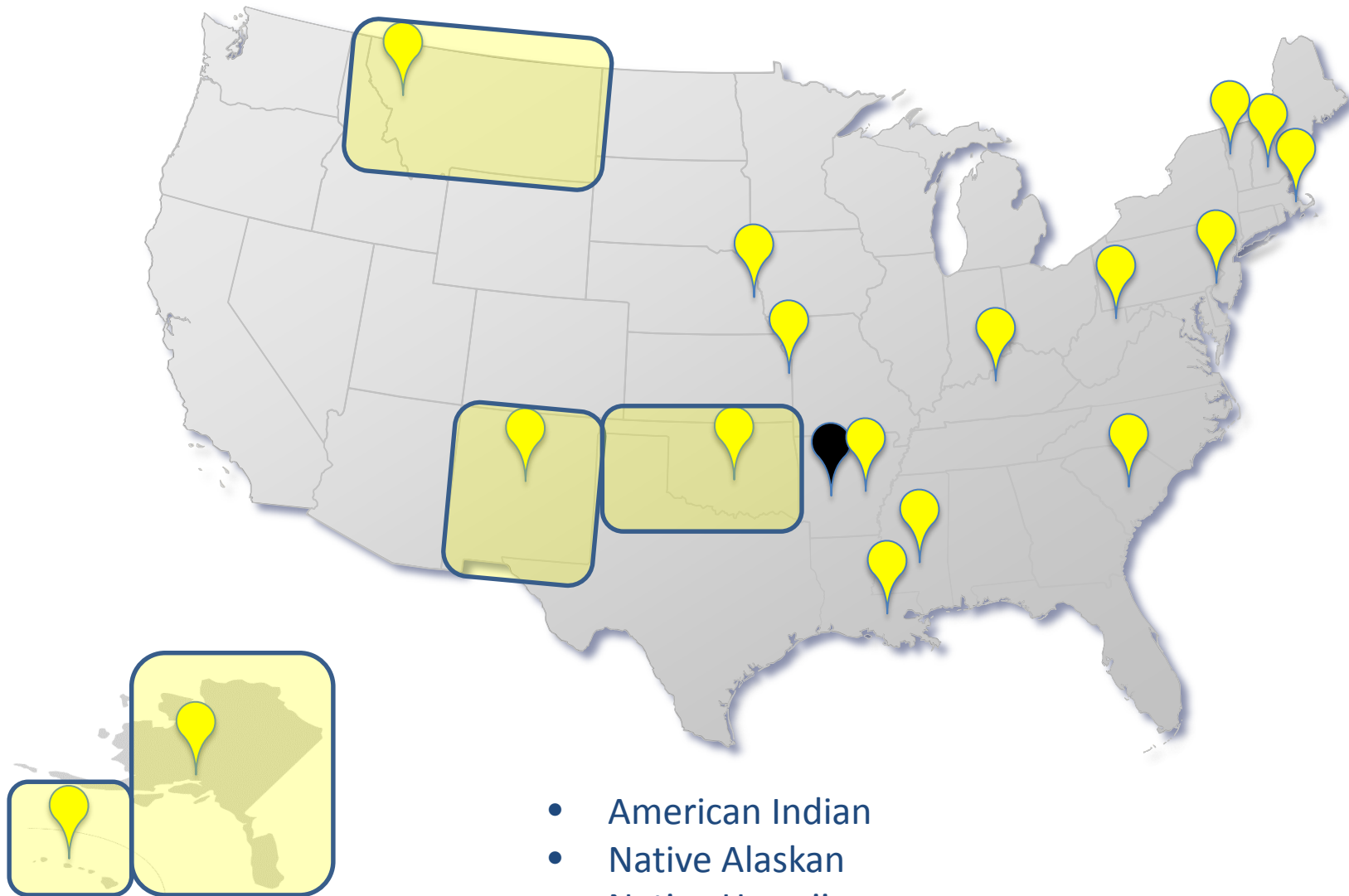


Clinical Sites

Data Coordinating and Operations Center (DCOC)

IDeA States Pediatric Clinical Trials Network

5 states with high % indigenous populations



- American Indian
- Native Alaskan
- Native Hawaiian

Getting the (Team)work Done

- Foster culture of collaboration



A word cloud developed at the NHLBI Center for Health Equity Promotion (CHEP) from the keywords associated to the ECHO model.



NIH in partnership role



Investigators drive
the science
...working groups...



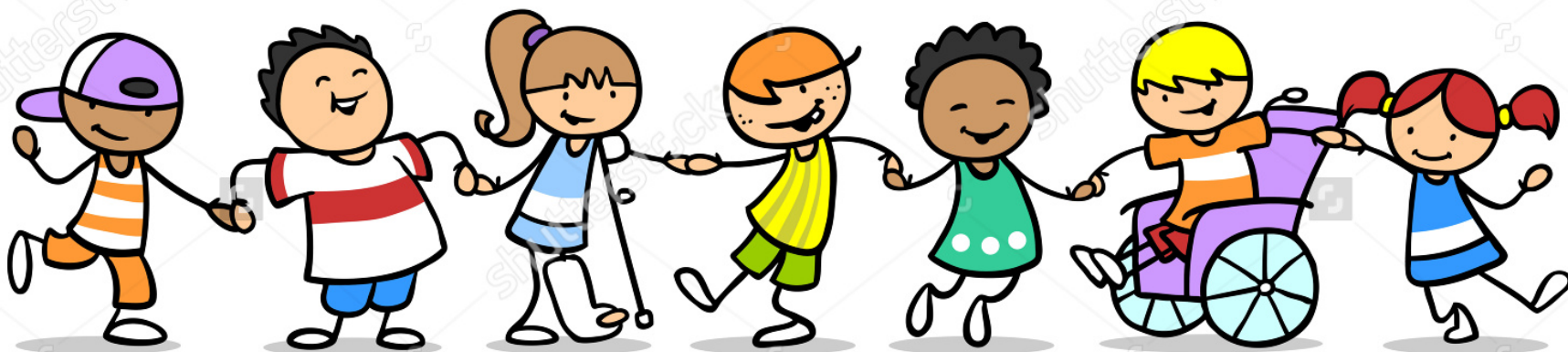
Getting the (Team)Work Done

- Guidance by External Scientific Board
 - Reports to NIH Director via Council of Councils
 - **Includes Dr. William Freeman, Northwest Indian College**

Long-term

- Conduct innovative observational and intervention research
 - Answer crucial questions about child health and development
 - Inform programs, policies, and practices that improve health of children and adolescents

Enhance the health of children for generations to come



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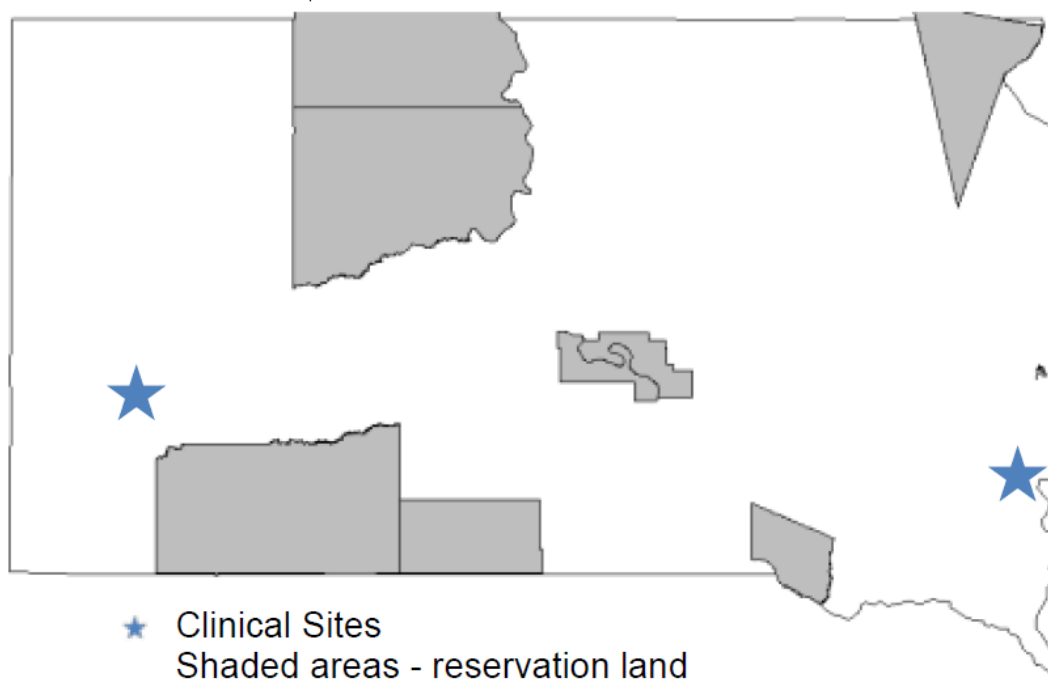
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Extra slides

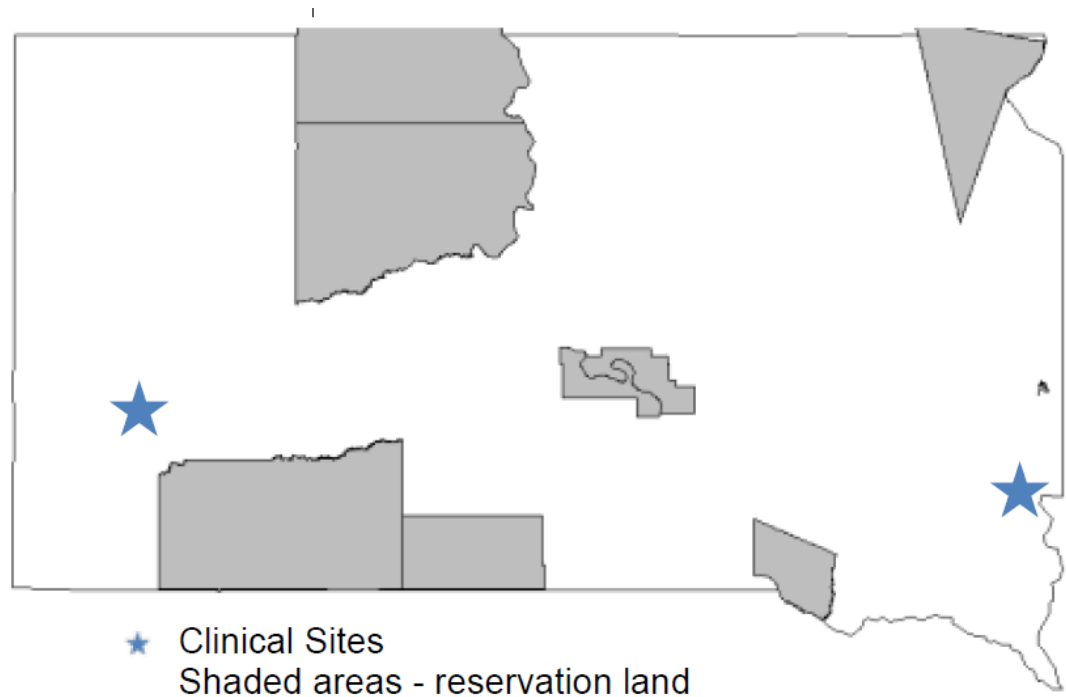
Ex 2: Prenatal Alcohol in Sudden Infant Death Syndrome and Stillbirth Network Safe Passage Study (PASS, A. Elliott, PI)

Figure 1. South Dakota Map



PASS

~25% AI/AN
~75% Non-Hispanic White



Relationships of prenatal exposure to tobacco, alcohol, drugs with

- Brain development
- Asthma

Within the social context of families

Disparities in Health Outcomes

South Dakota

	SD overall	SD Non-Hispanic White	SD AI/AN
Infant mortality (per 1K)	7.0	5.7	11.5
Obesity	32%	30%	47%
Asthma	7%	7%	12%