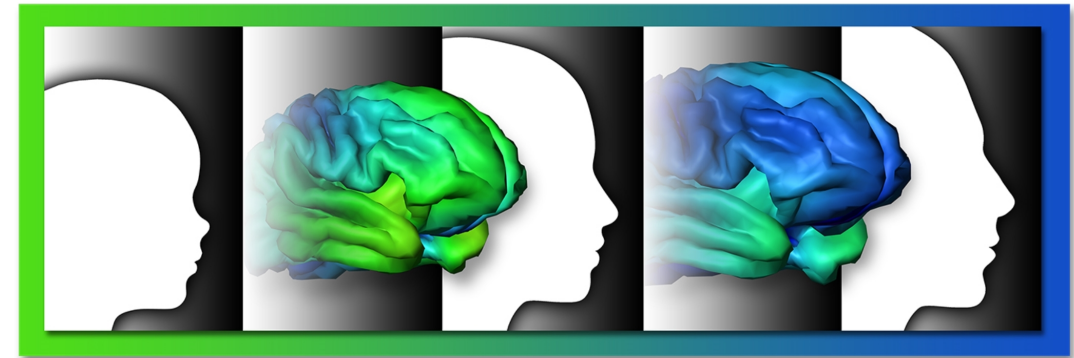# The case for collaborative, large scale studies and aggressive data sharing policies:
The ABCD Study Data Sharing Model

Terry Jernigan, PhD

Cognitive Science, Psychiatry, Radiology
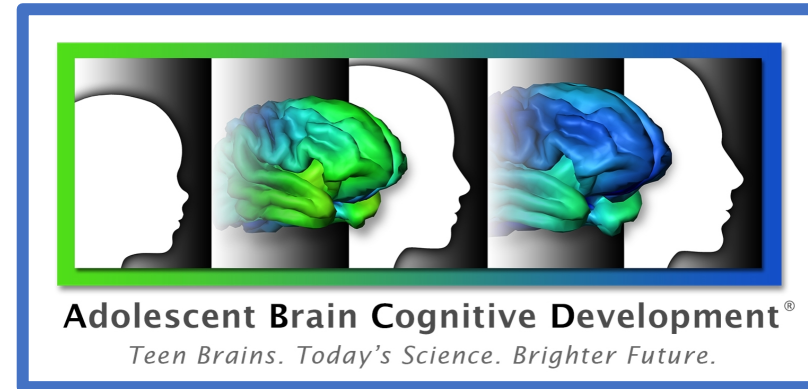
Center for Human Development

University of California, San Diego

Adolescent Brain Cognitive Development®

Teen Brains. Today's Science. Brighter Future.

The ABCD Study

Adolescent Brain Cognitive Development®
*Teen Brains. Today's Science. Brighter Future.*

The Adolescent Brain Cognitive Development (ABCD) Study® is the largest long-term study of brain development and child health in the United States. …

The ABCD Research Consortium consists of a Coordinating Center, a Data Analysis, Informatics & Resource Center, and 21 research sites across the country…

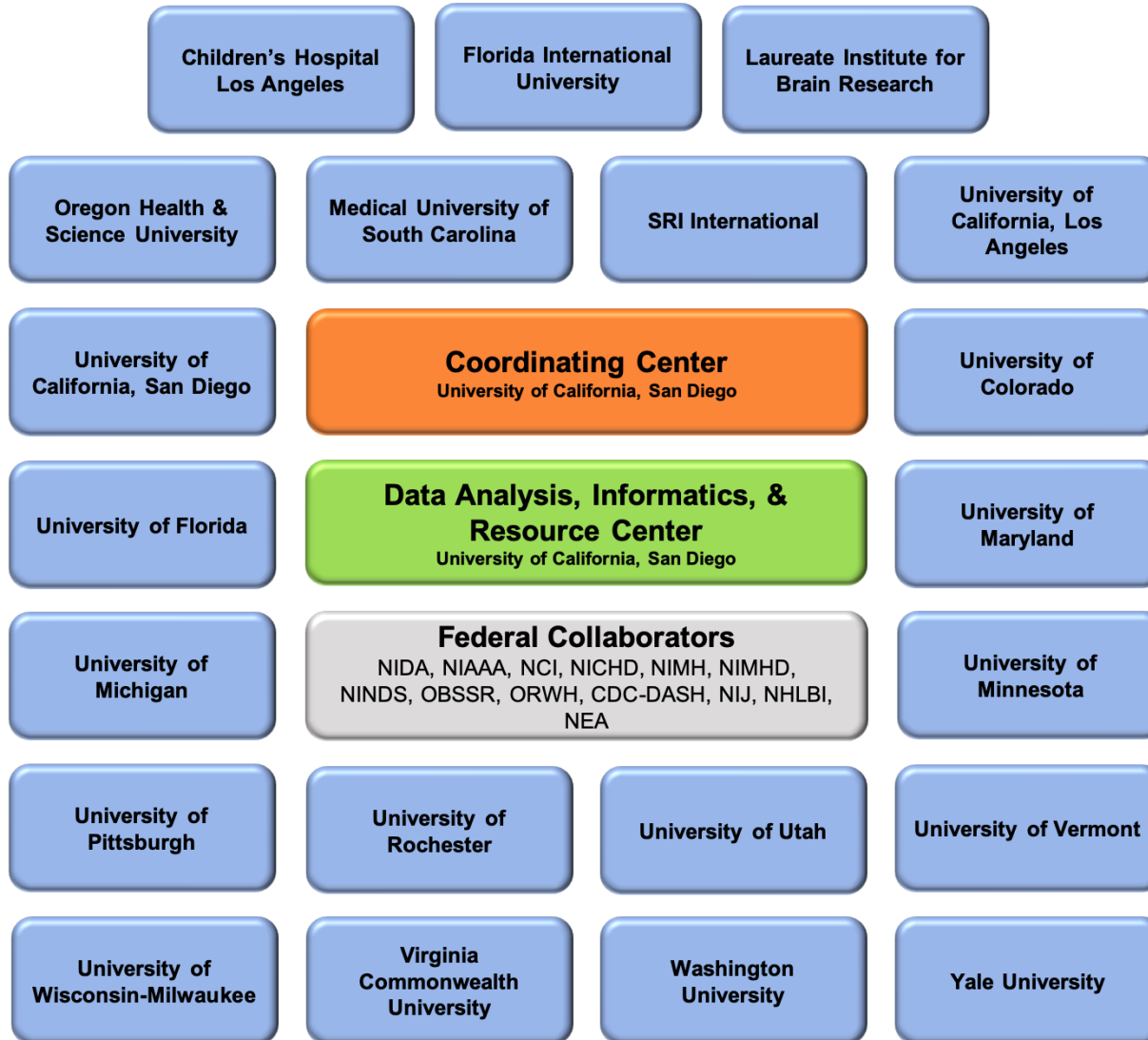…11,880 children ages 9-10 (and their caregivers) joined the study.

Researchers will track their biological and behavioral development through adolescence into young adulthood.

ABCD Study Aims
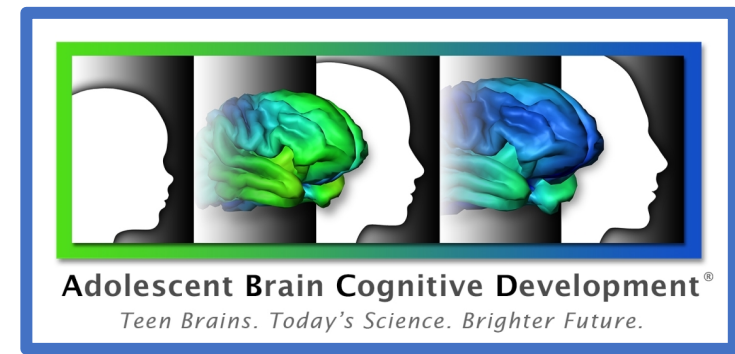
- Develop **national standards for normal brain development**

- Measure **individual developmental trajectories** (e.g., of brain, cognitive, and emotional development, academic progress), and identify factors that may influence them (protectively or adversely).

- Examine roles of **genetic vs. environmental factors, and interplay**.

- Study **effects of health, physical activity, sleep…..** on brain development and other outcomes.

- Study **onset and progression of mental disorders**, variability in course or severity; relationship between mental disorders and substance use.

- Determine how **substance use** affects developmental outcomes and vice versa.

Research Centers and Sites

|			
Children's Hospital Los Angeles	Florida International University	Laureate Institute for Brain Research	
Oregon Health & Science University	Medical University of South Carolina	SRI International	University of California, Los Angeles
University of California, San Diego	**Coordinating Center** University of California, San Diego		University of Colorado
University of Florida	**Data Analysis, Informatics, & Resource Center** University of California, San Diego		University of Maryland
University of Michigan	**Federal Collaborators** NIDA, NIAAA, NCI, NICHD, NIMH, NIMHD, NINDS, OBSSR, ORWH, CDC-DASH, NIJ, NHLBI, NEA		University of Minnesota
University of Pittsburgh	University of Rochester	University of Utah	University of Vermont
University of Wisconsin-Milwaukee	Virginia Commonwealth University	Washington University	Yale University

- Investigators: 190
- Federal collaborators: 42
- Research staff:
  - 500+ so far (2022)
- External advisors: 25
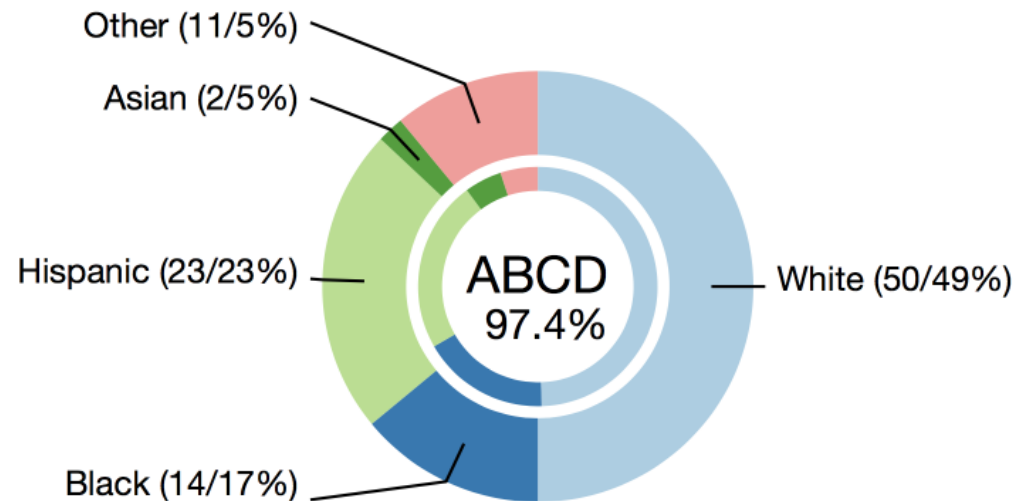
ABCD's National Scope
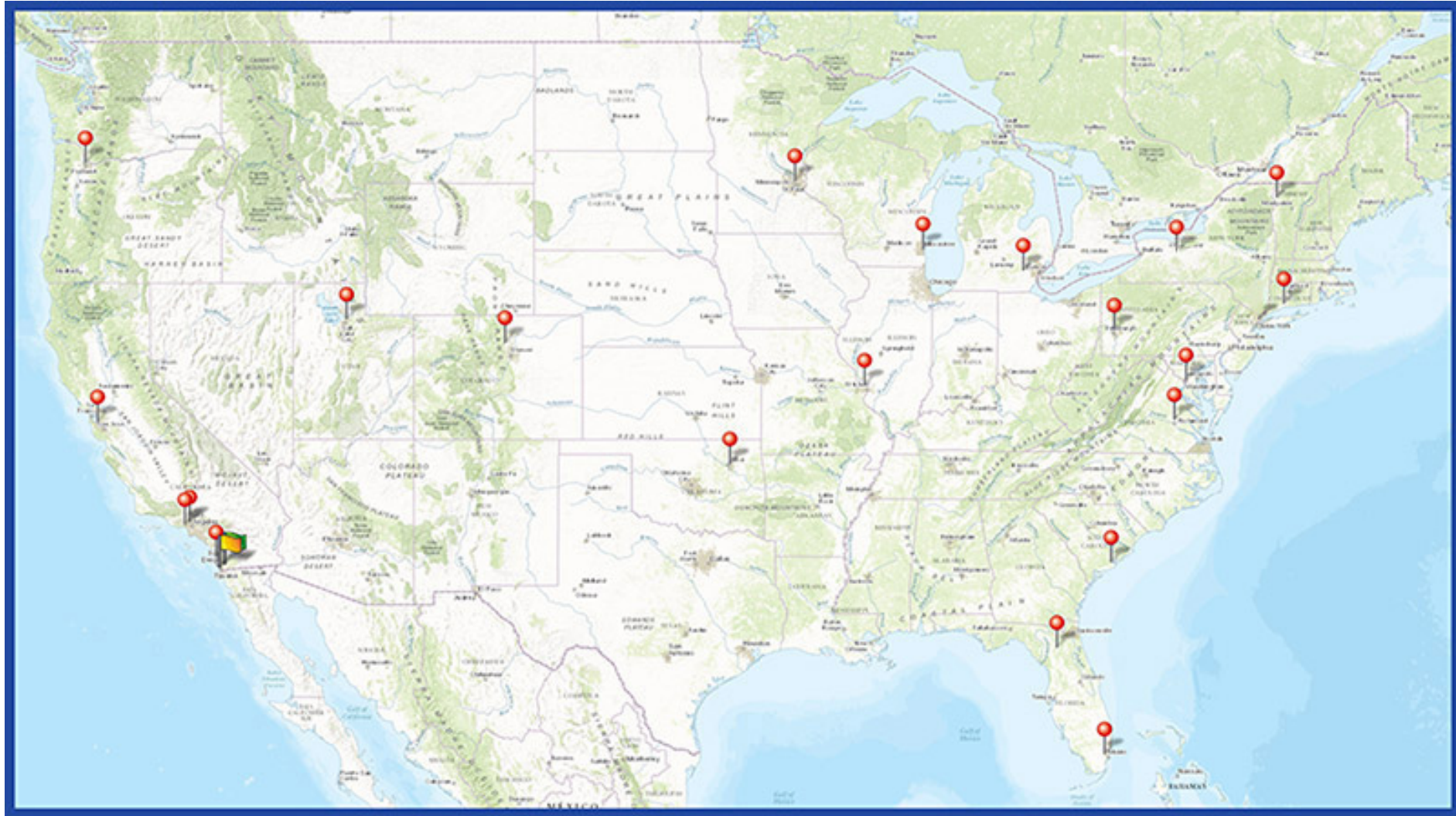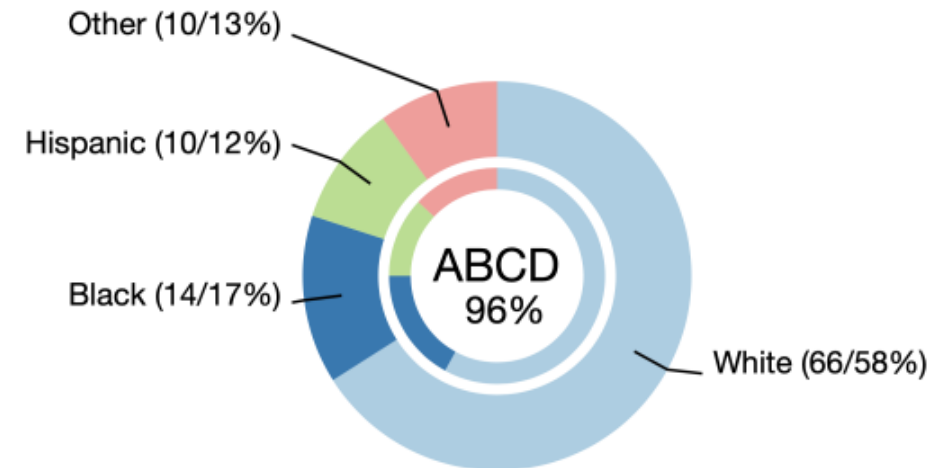
Diverse Cohort
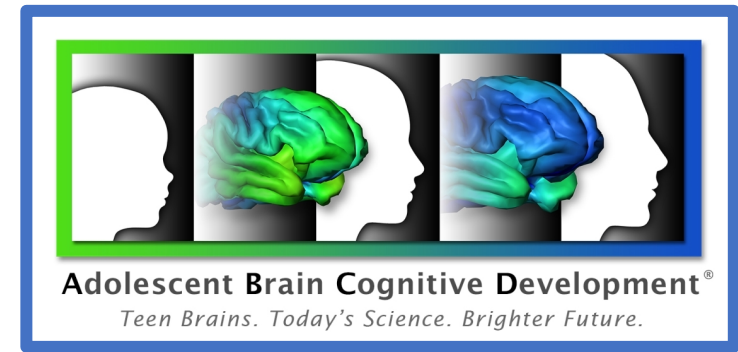
- **11,880 children, aged 9-10, were enrolled**
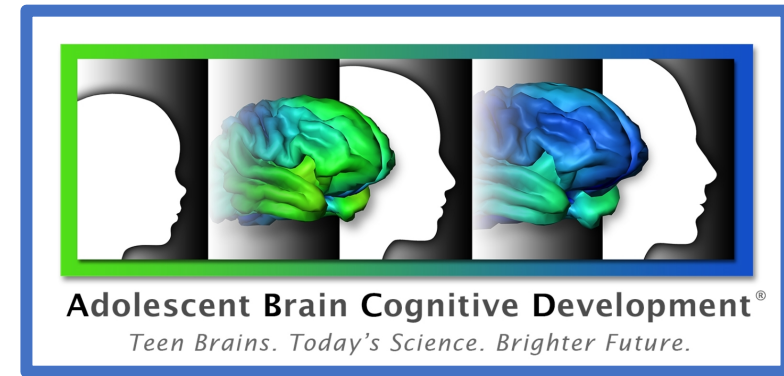 - The cohort composition largely matches the targets set for us by our epidemiology consultants.

N = 10,150, General Population Enrollments

N = 1730, Birth/Twin Registry

Visit Schedule

Adolescent Brain Cognitive Development®
Teen Brains. Today's Science. Brighter Future.

- Comprehensive assessments at baseline and biennial follow up visits (including multimodal imaging)

- Briefer assessments at face-to-face interim year visits

- More frequent phone/web assessments

The Adolescent Brain and Cognitive Development (ABCD) Study is "Population Neuroscience"
Why do it?

One important reason:

An alarming rate of replication failure (including effect size distortion) in the biomedical and biobehavioral literatures.
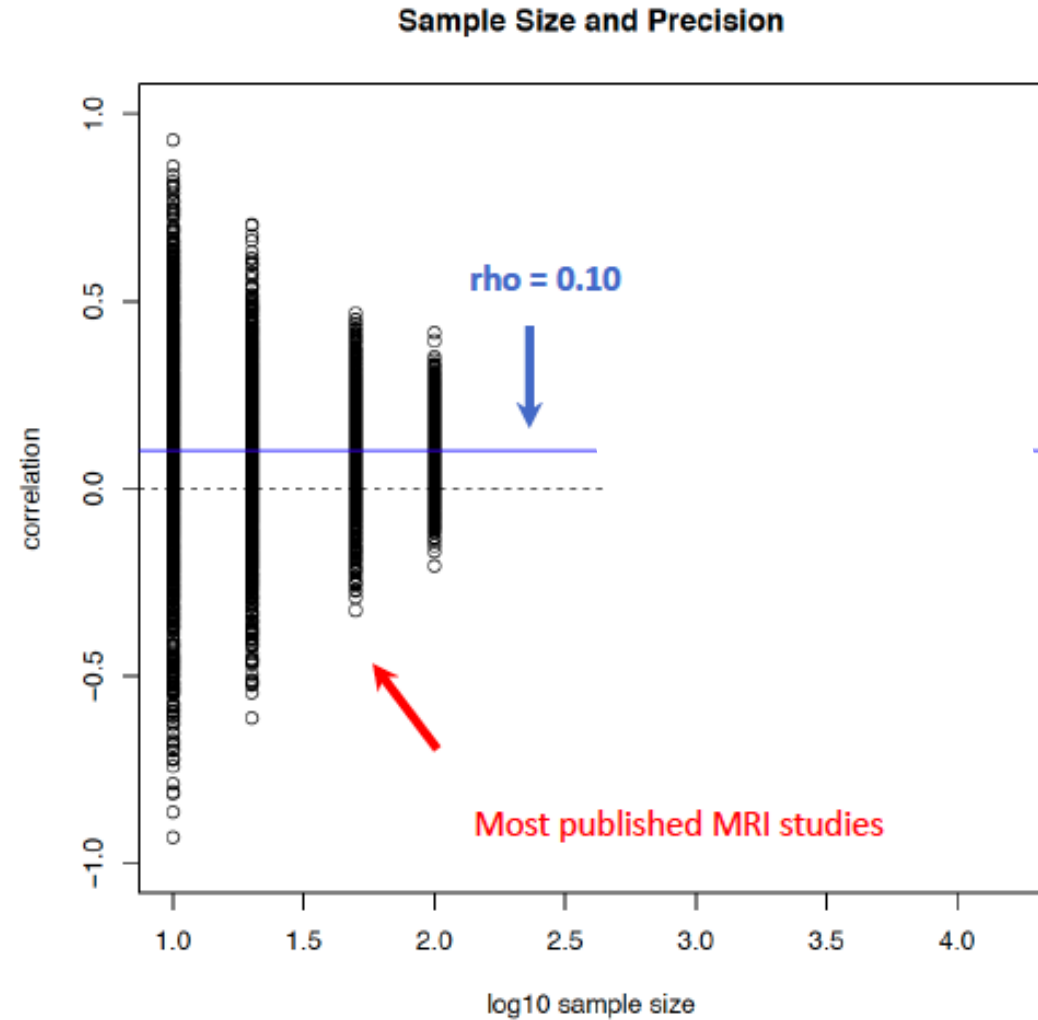
A Word about Replicability

(Button, et al., 2013)

- Replicability: effects are "similar" if estimated in comparable independent samples

Sample Size and Precision

rho = 0.10

Most published MRI studies

correlation

log10 sample size

A Word about Replicability

- Replicability: effects are "similar" if estimated in comparable independent samples

- The broadly-based sampling frame and large size of ABCD directly impact the low replication rates that afflict neuroscience research (Button, et al., 2013).
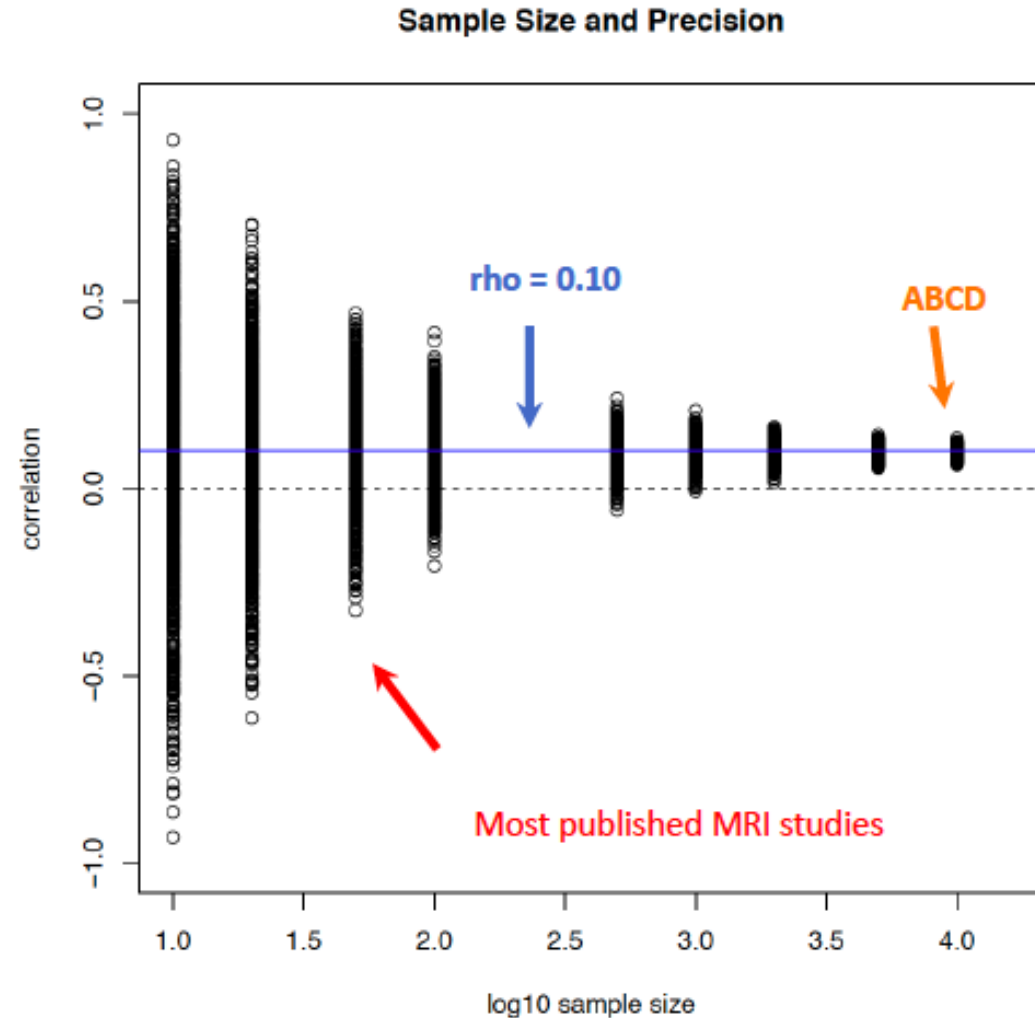
*Slide borrowed from Wes Thompson

Sample Size and Precision

ABCD Open Science Model

A Unique Resource for the Entire Scientific Community

https://data-archive.nimh.nih.gov/abcd

ABCD Study Fast Track Data

Unprocessed neuroimaging data & basic participant demographics (age, sex)

➢ Currently available

Annual Curated Data Release

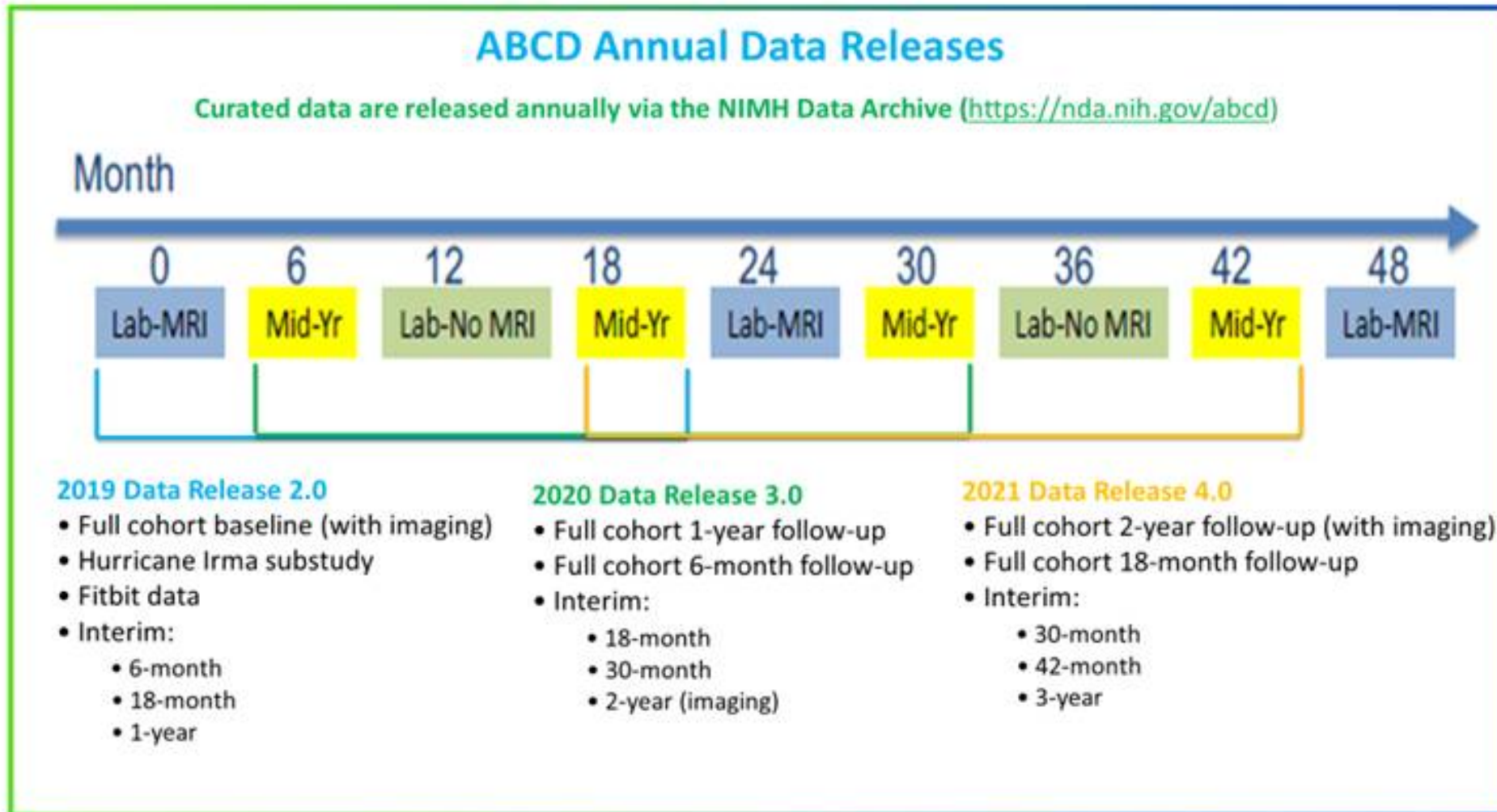Annual release of curated data, including all assessment domains and many computational analysis pipelines.

➢ 1.0 Released in **2018** with the first 4500+ participants

➢ 2.0 Released in **2019** with 11,800+ participants

➢ 3.0 Released in **2020** with several thousand 2 year FU visits

➢ 4.0 Released in **2021** with interim follow-up data

For more information on ABCD data sharing:

https://abcdstudy.org/scientists.html

ABCD Open Science Model

ABCD Annual Data Releases

Curated data are released annually via the NIMH Data Archive (https://nda.nih.gov/abcd)

Month

0	6	12	18	24	30	36	42	48
Lab-MRI	Mid-Yr	Lab-No MRI	Mid-Yr	Lab-MRI	Mid-Yr	Lab-No MRI	Mid-Yr	Lab-MRI

2019 Data Release 2.0
- Full cohort baseline (with imaging)
- Hurricane Irma substudy
- Fitbit data
- Interim:
  - 6-month
  - 18-month
  - 1-year

2020 Data Release 3.0
- Full cohort 1-year follow-up
- Full cohort 6-month follow-up
- Interim:
  - 18-month
  - 30-month
  - 2-year (imaging)

2021 Data Release 4.0
- Full cohort 2-year follow-up (with imaging)
- Full cohort 18-month follow-up
- Interim:
  - 30-month
  - 42-month
  - 3-year

ABCD Open Science Model Access

- The ABCD Data Resource is a restricted-access, de-identified data set accessible to researchers at institutions with 'federal wide assurance'.

- Prospective users apply online at NDA where they describe their planned uses of the data and sign a data use agreement that prohibits re-sharing, re-identification attempts, and inappropriate or disrespectful reporting of disaggregated data. They also agree to report published data to NDA.

- They then apply for endorsement through their institutions.

- Data use agreements are co-signed by institutional officers at the recipients' institutions and when approved are valid for one year.

- Renewals (continued authorization to use the data) are contingent upon compliance with the data use agreement.

ABCD Open Science Model Community Response

- The NIMH Data Archive reports that at the end of 2021:
  - Over 3700 unique users were authorized users of ABCD Data.
  - 32 countries are home to user institutions
  - Users download an average of 115 terabytes of data per month.
- 181 authors from outside, compared to 130 from inside, the consortium have published from ABCD data.
- Last year alone over 142 publications resulted from ABCD data, more than half from outside investigators.
- Many grants (over 70) proposing to use ABCD data have been funded.

Windfall Scientific Benefits…
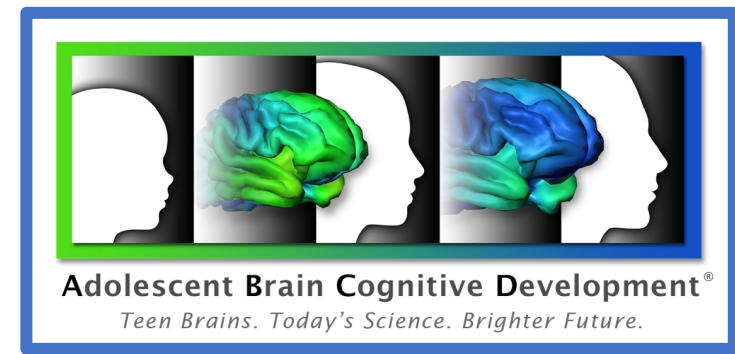
- Olerich, K et al. (2022). Association of maternal diabetes with offspring childhood hypothalamic gliosis. American Journal of Obstetrics & Gynecology, 226(1)

- Nwotchouang et al. (2021) Imaging and health metrics in incidental cerebellar tonsillar ectopia: findings from the Adolescent Brain Cognitive Development Study (ABCD). Neuroradiology 63: 1913–1924.

- Naqvi S et al. (2021) Shared heritability of human face and brain shape. Nat Genet 53: 830–839

- Sewaybricker et al. (2021) Greater radiologic evidence of hypothalamic gliosis predicts adiposity gain in children at risk for obesity. Obesity 29(11):1770-1779.

- Kaplan CM et al. (2021) Neurobiological antecedents of multisite pain in children. Pain [Epub ahead of print] 34382607

ABCD Open Science Model
Involvement of Junior Investigators

Graduate students, postdocs, and young investigators are lead authors on a large proportion of ABCD publications, and this is true both for publications by outside investigator groups and ABCD investigators.

Co-mentoring of trainees by faculty investigators at different sites is common, both formally and informally.

Scientific Training in Addiction Research Techniques (START)

START aims to:

- Recruit early-stage scholars who are BIPOC
- Train fellows to access, analyze, and disseminate ABCD data
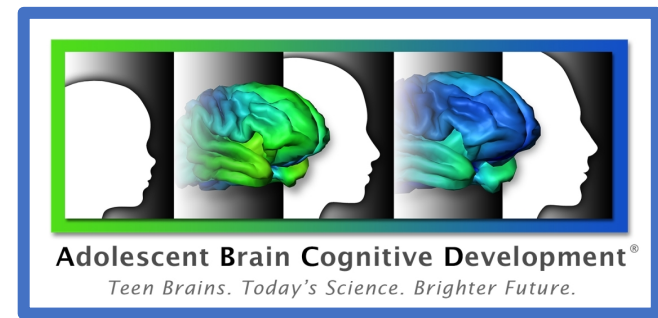- Facilitate mentored independent research experiences

Five pillars

- 1) Recruitment, 2) enrichment, 3) training, 4) effective mentoring, and 5) nourishing environments

Creating a supportive community!

*Slide borrowed from Directors Hugh Garavan and Micah Johnson

In conclusion…

- Developmental population neuroscience is a new, highly collaborative, way to do human developmental and biomedical research.

- The advantage is that many potentially important factors that may influence the development of the child, and affect important outcomes, can be measured in real time.

- The result is a very large and high dimensional data resource.

- The increase in power means that effects of biological, environmental, and behavioral factors (and their interactions) on important outcomes can be more accurately estimated.

In conclusion…
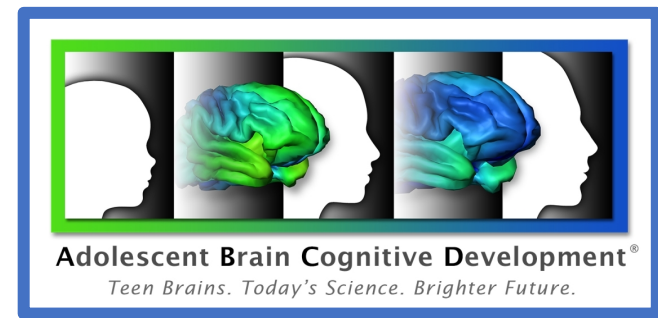
Open science is accelerating the progress and increasing the impact of our work:

- By increasing the number, disciplinary range, and diversity of users of the data.

- Ensuring the transparency needed to resolve inconsistencies in the reported results

- Lowering barriers for junior investigators to contribute to the literature with major publications

Thanks!

Questions?