ABCD STUDY® SCIENCE: ADVANCING DISCOVERY WITH INTEGRITY AND RESPECT FOR STUDY PARTICIPANTS

We are committed to correctly representing our participants and using study results to help youth in the future. To do that, it is important for scientists to use data responsibly, which helps ensure that study results are accurate and maintains public trust in research.

This infographic explains:

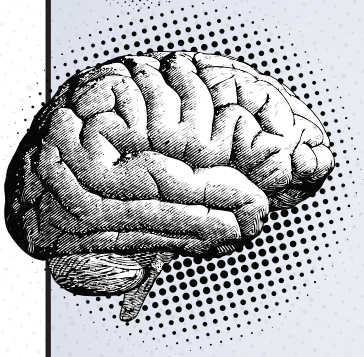
- What responsible data use is
- How scientists use data responsibly
- What you can do to be responsible with data, too

THE ADOLESCENT BRAIN COGNITIVE DEVELOPMENT℠ (ABCD) STUDY IS A LONG-TERM STUDY OF YOUTH AS THEY GROW.

NEARLY 12,000 YOUTH ARE PARTICIPATING AT **21 STUDY LOCATIONS** ACROSS THE UNITED STATES.

UNDERSTANDING DATA

DATA



Participant information becomes study **data**.

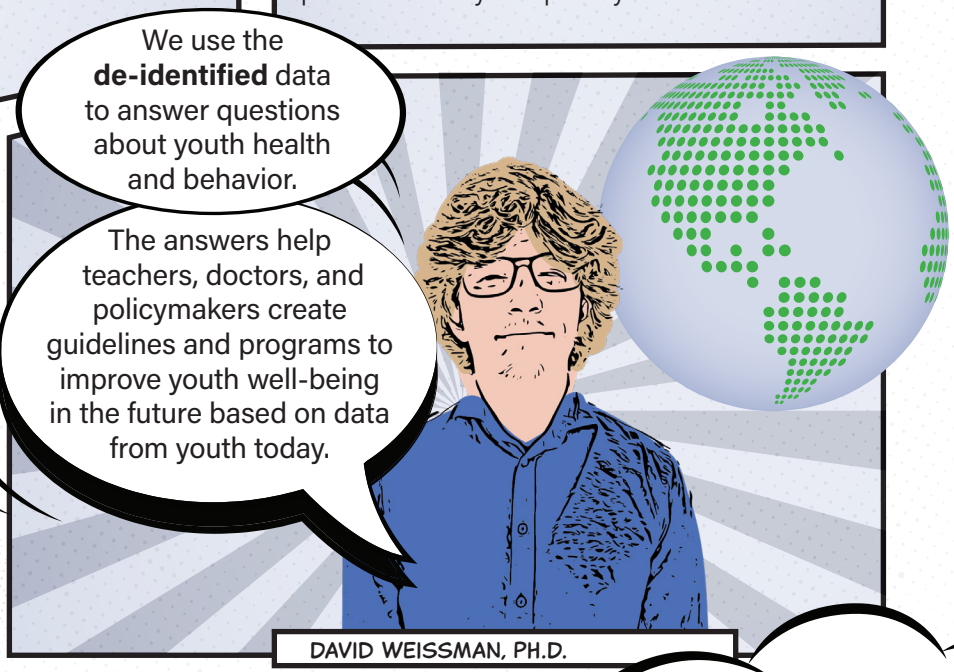
Data may include MRI scans, survey answers, activity information (like step counts), biosamples (such as blood and saliva samples), and personal details like race or family income.

DE-IDENTIFIED DATA

Scientists **de-identify** participant data before sharing it with other scientists. This means that details like names and addresses have been removed from the data to protect each person's identity and privacy.

BIG DATA

ABCD is a **big data** study with many participants from many backgrounds. Big data studies include large amounts of information analyzed with advanced computing tools.



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

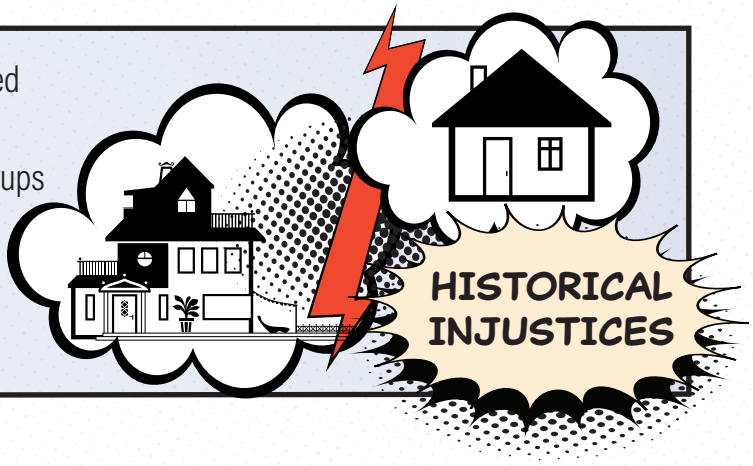
PROMOTING DIGNITY AND RESPECT FOR PARTICIPANTS

PROMOTING DIGNITY AND RESPECT FOR PARTICIPANTS AND COMMUNITIES LEADS TO RIGOROUS AND IMPACTFUL SCIENCE.

It's a good idea to use language that is not judgmental.

Some communities do not trust how their data will be used because of **historical injustices**, including:

- Dividing neighborhoods unfairly (redlining) so some groups cannot get homes, financial help, or health care.
- Experimenting on people who cannot consent to research, like people experiencing incarceration.

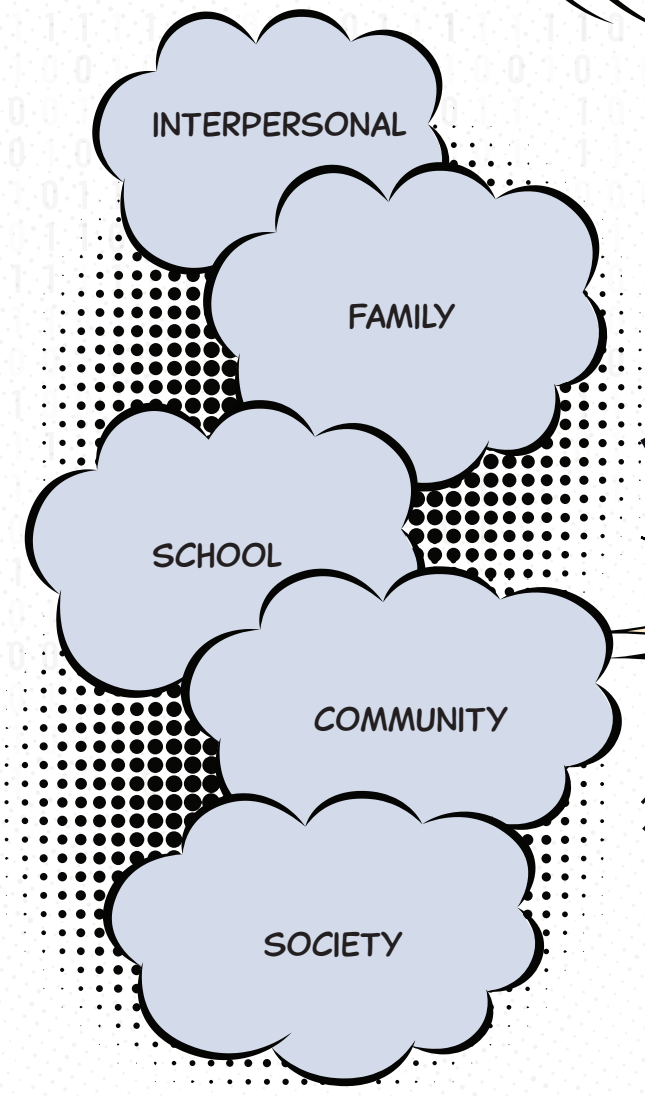


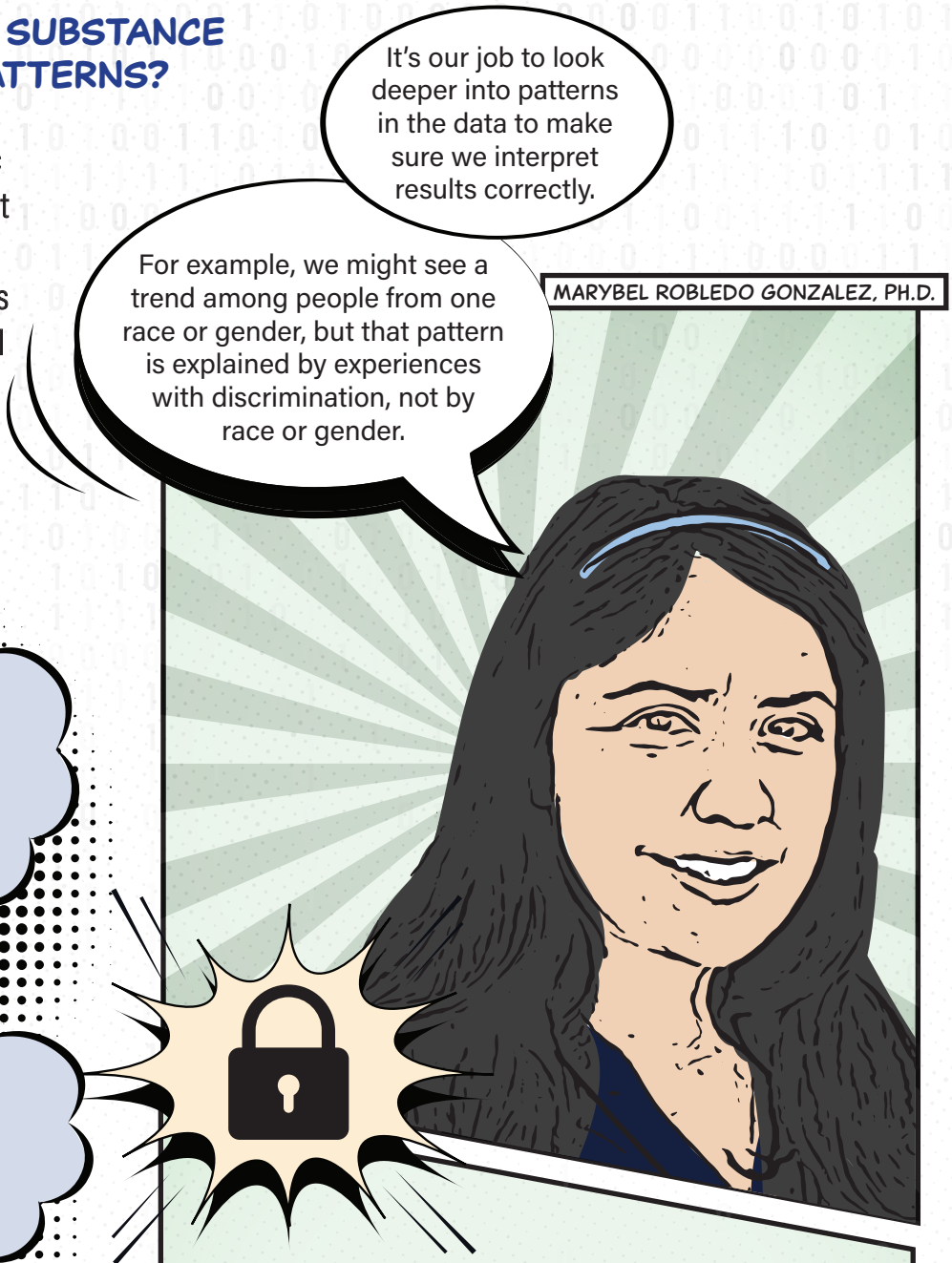
LEARN ABOUT THE ETHICAL ISSUES BEHIND THE TUSKEGEE STUDY. THIS STUDY IS AN EXAMPLE OF A HISTORICAL INJUSTICE.

INTERPRETING DATA IN A RESPONSIBLE WAY

WHAT FACTORS AFFECT SUBSTANCE USE BEHAVIORS AND PATTERNS?

Rather than focusing on demographic factors (e.g., gender, race, employment status, income), it's better to look at substance use behaviors and patterns in a broader way that considers social and environmental factors that may raise or lower risk of substance use.





Scientists working with ABCD Study data participate in training on responsible data use to learn about:

- Understanding historical injustices, particularly in science, to help them approach data with greater awareness about historical context and responsibility for doing ethical research
- Paying attention to assumptions and biases that may contribute to how people are put into categories
- Exploring scientific questions about ways youth and communities can thrive

RESPONSIBLE USE OF ABCD DATA IN PUBLISHED PAPERS

"Recommendations for the responsible use and communication of race and ethnicity in neuroimaging research"

2024 Carlos Cardenas-Inigues and Marybel Robledo Gonzalez

What the guidelines suggest

USING RACE AND ETHNICITY RESPONSIBLY BY RECOGNIZING THEM AS SOCIAL CONSTRUCTS, AVOIDING THEIR USE AS PROXIES FOR SOCIAL FACTORS, AND FOCUSING ON HEALTH EQUITY.

"The inequitable distribution of economic resources and exposure to adversity between racial groups contribute to mental health disparities within the United States."

2024 Nathaniel Harnett et al.

What the research suggests

UNEQUAL ACCESS TO FINANCIAL RESOURCES AND EXPERIENCES OF ADVERSITY ARE RELATED TO DIFFERENCES IN MENTAL HEALTH BETWEEN RACIAL GROUPS.

"Characteristics, such as cost of living and state-level anti-poverty programs, relate to the magnitude of socioeconomic disparities in brain development and mental health."

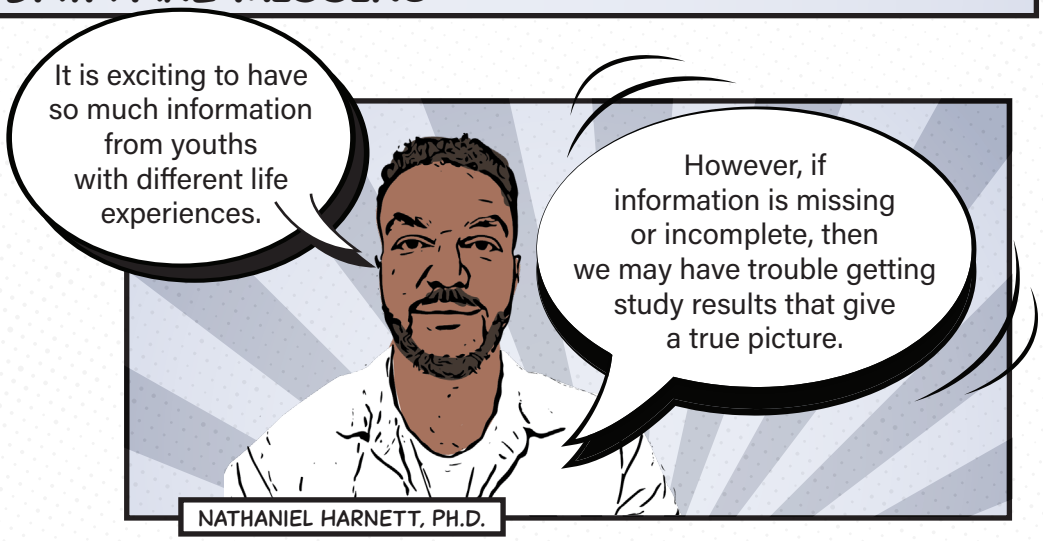
2023 David Weissman et al.

What the research suggests

FINANCIAL ASSISTANCE PROGRAMS REDUCE GAPS IN MENTAL HEALTH AND BRAIN DEVELOPMENT BETWEEN LOW-INCOME AND HIGH-INCOME FAMILIES.

WHEN IMPORTANT DATA ARE MISSING

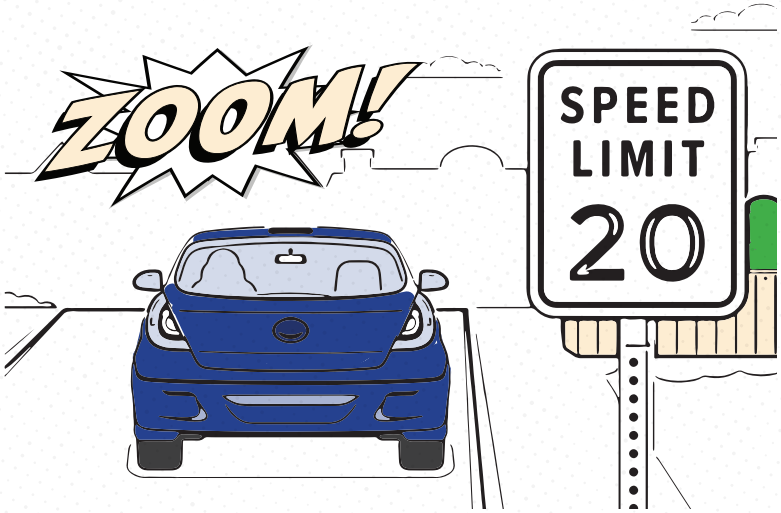
MISSINGNESS IS WHEN THE COLLECTED STUDY DATA ARE INCOMPLETE. THIS MAY BE DUE TO WHO DOES OR DOESN'T RESPOND TO A SURVEY. MISSINGNESS ISN'T ALWAYS PROBLEMATIC, BUT IN SOME CASES THERE'S A PATTERN OF MISSING DATA THAT CAN AFFECT STUDY RESULTS.



DATA MISSINGNESS

Here's an example: A scientist might want to know how many teens speed while they drive. They may ask how many speeding tickets a sample of teens has received. Teens who are embarrassed about their speeding tickets might not report this information at all, leaving only answers from teens with no speeding tickets.

Information is missing. This leads to an underestimate of the true number of speeding tickets received by teens in the sample.



MISSING DATA CAN THREATEN DATA GENERALIZABILITY

GENERALIZABILITY IS HOW ACCURATELY FINDINGS FROM A RESEARCH STUDY APPLY TO A BROADER POPULATION.

GENERALIZABILITY

STOP

In the ABCD Study, we ask:
Can these findings be generalized, or applied, to different groups of teens?

DATA BIAS

IF SCIENTISTS DON'T THOUGHTFULLY ADDRESS MISSING DATA, STUDY RESULTS CAN BE BIASED.

CONSIDERING THE SOURCE OF INFORMATION

SCIENTISTS NEED TO DO THEIR PART BUT IT IS ALSO IMPORTANT FOR YOU TO MAKE SURE THE SOURCE OF INFORMATION YOU READ IS RELIABLE BEFORE TRUSTING ITS CONCLUSIONS.

THE **LEAN** APPROACH HELPS PEOPLE THINK ABOUT WHAT THEY WATCH, READ, OR HEAR, AND DECIDE WHETHER AN INFORMATION SOURCE IS ACCURATE AND TRUSTWORTHY.

- **L**anguage
- **E**vidence
- **A**uthor
- **N**eutrality

LANGUAGE

Carefully consider the **language** used in a headline, research paper, news article, or other source.

Ask yourself:
Are they using emotional words or leading words? Are they exaggerating the study results? Do they state facts?

"Screen use RUINS teens' brains"

The words people use matter and influence the message.

EVIDENCE

- The information should be backed up by evidence to help ensure credibility.
- Two things can be related without one causing the other (like a rooster crowing and sunrise).
- Sometimes it can be hard to know the direction of a relationship between two things, like exercise and happiness. Does exercise lead to feeling happier, or are happier people more likely to exercise?

Ask yourself:
Do the data support the conclusion? Does the conclusion make sense?

"Excessive screen use CAUSES depression."

AUTHOR

Trust in the **author** is important—the source matters.

Ask yourself:
Do they have knowledge and experience in the topic? What website posted the information? Is the author a health care provider, a scientist, a journalist? What are their qualifications?

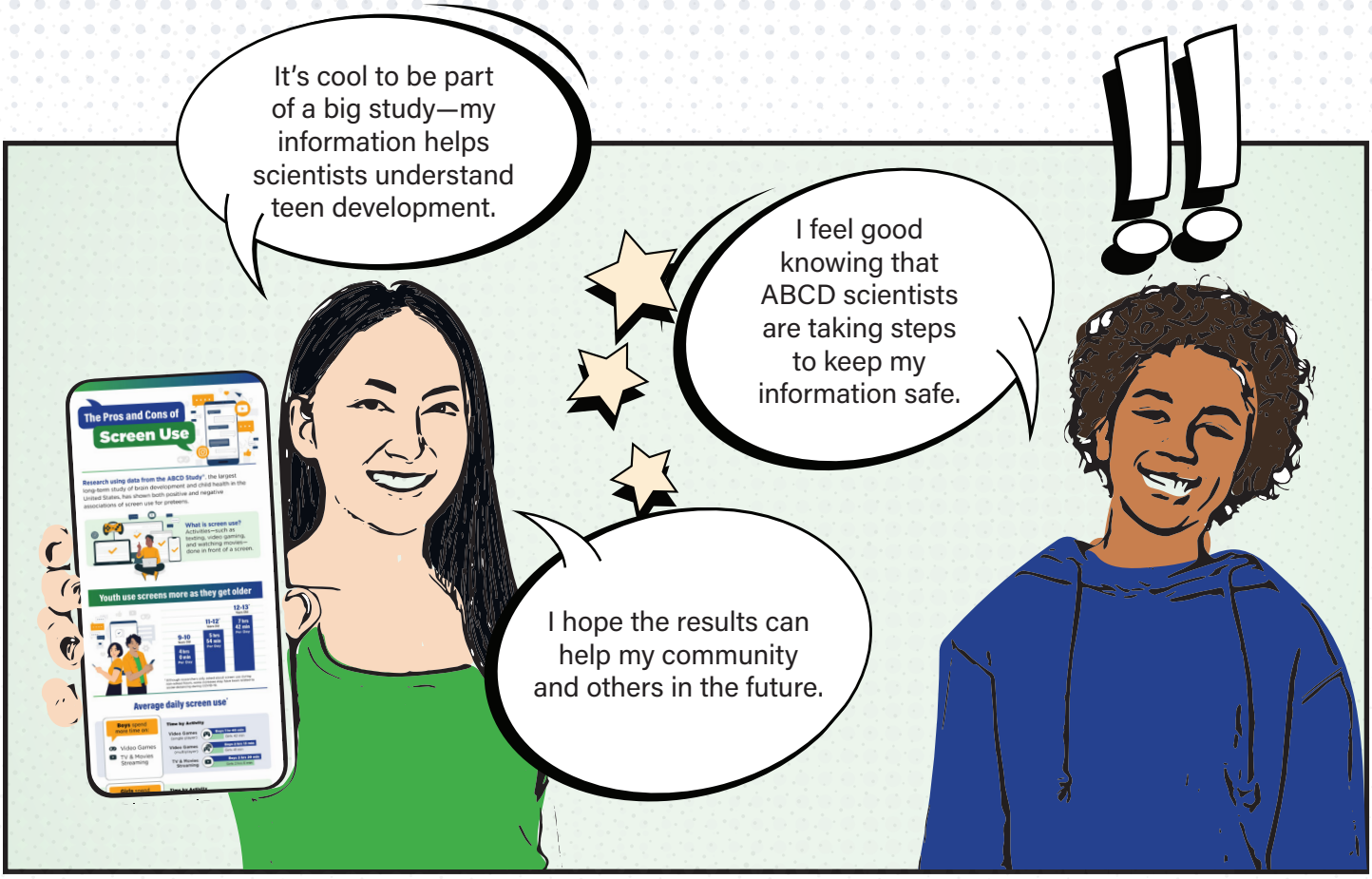
You can check to make sure the author's expertise matches the topic.

ARTICLE:
IS THIS LEGIT?
ACCESSING VALID AND RELIABLE HEALTH INFORMATION

NEUTRALITY

Look for **neutral** information and recognize when articles are one-sided.

Ask yourself:
Is the author stating facts or are they trying to convince you of something? Does the author have an agenda they are trying to push?



KEY WORDS

GLOSSARY

Data: measurable information that can be counted or put into distinct categories

Big data: very large amounts of information that require complex analytic tools to answer research questions

De-identified: type of data that has personal information removed

Evidence: facts and information based on data

Valid: scientifically supported and accurate information

Bias: one-sided or slanted views that do not represent information objectively

Missingness: some data are included but other data are missing or were not collected

Generalizability: how well findings from a research study apply to a broader population

Stigmatizing: instigating or promoting marginalization or discrimination of a person or group of people

This information is made possible by the Adolescent Brain Cognitive Development℠ Study. ABCD-supported studies let us learn more about how the brain develops, which can lead to improving the health and well-being of children now and for future generations. Scientists have published more than 1,000 papers using ABCD data.

Learn more: **abcdstudy.org/families**

RELATED ARTICLES

Anti-Poverty Programs May Help Reduce Disparities in Brain Development and Mental Health Symptoms in Children
https://nida.nih.gov/news-events/news-releases/2023/05/anti-poverty-programs-may-help-reduce-disparities-brain-development-mental-health-symptoms-children

State Anti-Poverty Programs Help Kids' Brains Stay Healthy
https://www.usnews.com/news/health-news/articles/2023-05-03/state-anti-poverty-programs-help-kids-brains-stay-healthy

New Study Reveals the Effect of Racism and Poverty on Children's Brains
https://www.pbs.org/newshour/show/new-study-reveals-the-effect-of-racism-and-poverty-on-childrens-brains

Study Finds Childhood Adversity Linked to Brain Differences in White, Black Children
https://psychiatryonline.org/doi/10.1176/appi.pn.2023.03.2.7

How to Use Race and Ethnicity Data Responsibly in Neuroscience Research
https://www.thetransmitter.org/community/how-to-use-race-and-ethnicity-data-responsibly-in-neuroscience-research/

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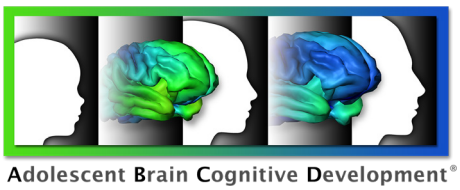
Chaarani B., et al. 2021. Baseline brain function in the preadolescents of the ABCD Study. *Nature Neuroscience*. 24:1176–1186. https://pubmed.ncbi.nlm.nih.gov/34099922/

Harnett N.G., et al. 2024. Population-level normative models reveal race- and socioeconomic-related variability in cortical thickness of threat neurocircuitry. *Communications Biology*. 7:745. https://www.nature.com/articles/s42003-024-06436-7

Robledo Gonzalez M., Cardenas-Iniguez C. 2024. Recommendations for the responsible use and communication of race and ethnicity in neuroimaging research. *Nature Neuroscience*. 27:615–628. https://www.nature.com/articles/s41593-024-01608-4

Robledo Gonzalez M., et al. 2024. Responsible research in health disparities using the Adolescent Brain Cognitive Development℠ (ABCD) Study. *Developmental Cognitive Neuroscience*. https://www.sciencedirect.com/science/article/pii/S1878929324001580. https://doi.org/10.1016/j.dcn.2024.101497

Weissman D.G., et al. 2023. State-level macro-economic factors moderate the association of low income with brain structure and mental health in U.S. children. *Nature Communications*. 14:2085. https://www.nature.com/articles/s41467-023-37778-1



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