

# NBDC Responsible Data and Biospecimen Use Training

## 1. Introduction

### 1.1 NIH Brain Development Cohorts (NBDC)

Adolescent Brain Cognitive Development  
1000 Brains. Today's Science. Brighter Future.

NBDC  
NIH BRAIN DEVELOPMENT COHORTS

HEALTHY Brain and Child Development  
Babies - Brains - Bright Futures

## NIH Brain Development Cohorts (NBDC) Responsible Data and Biospecimen Use Training

This training provides information about ethical and responsible use of data and biospecimens from large datasets, such as the Adolescent Brain Cognitive Development<sup>SM</sup> (ABCD) Study and the HEALthy Brain and Child Development (HBCD) Study.

**At the end of the training, we will test your knowledge of its content.**  
Once you pass the assessment, you will be given access to the NBDC data.  
Please note that in order to pass the assessment, you must achieve at least 90% accuracy.

NIH National Institute on Drug Abuse

Continue


Notes:

## 1.2 What are the NIH Brain Development Cohorts?

### What are the NIH Brain Development Cohorts?


The NIH Brain Development Cohorts (NBDC) include two large prospective developmental studies supported by multiple Institutes and Centers at the NIH and other federal collaborators:

Adolescent Brain Cognitive Development<sup>SM</sup> (ABCD) Study



Adolescent Brain Cognitive Development<sup>SM</sup>  
*Teen Brains. Today's Science. Brighter Future.*

HEALTHy Brain and Child Development (HBCD) Study



HEALTHy Brain and Child Development  
*Babies · Brains · Bright Futures*

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 1 of 8


## 1.3 What is The ABCD Study®?

### What is The ABCD Study®?

**The Adolescent Brain Cognitive Development<sup>SM</sup> (ABCD) Study** is the largest prospective study of adolescent health and brain development in the United States.

The study assesses factors that influence individual brain development trajectories and functional outcomes by following nearly 12,000 youth across the country for at least 10 years, beginning when they were 9-10 years old.

Data collected from ABCD Study<sup>®</sup> participants are made available to the broader scientific community via an open science model. Data are de-identified before being shared. Researchers from around the globe can query the data and pursue answers to their own scientific questions.



[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 1 of 8

## 1.4 What is the HBCD Study?

**What is the HBCD Study?**

**The HEALTHy Brain and Child Development (HBCD) Study** is the largest long-term study of early brain and child development in the United States.

The HBCD Study will enroll over 7,000 participants and follow them from pregnancy through the first ten years of life to understand how the brain develops and is affected by exposure to substances and other environmental, social, and biological factors during pregnancy and after birth. Enrollment is expected to be completed by 2027.

De-identified data will be released annually through an open science model. HBCD Study features data from questionnaires, neuroimaging, EEG, cognitive and behavioral assessments, growth measurements, biospecimens, wearable sensors, and electronic medical records.



[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) [1 of 2](#)


Notes:

## 1.5 How representative are the ABCD and HBCD samples? (1/2)

**How representative are the ABCD and HBCD samples? (1/2)**

The recruitment procedures for these studies were carefully designed and implemented to reflect the demographics of the United States population, but researchers should be aware of inherent limits to the generalizability of the study samples.

The HBCD and ABCD samples, while population-based, should not be described as representative<sup>1,2</sup> of the United States population. Invitations to eligible participants were restricted to the locations of the study sites, certain exclusion criteria were applied, and participants self-selected into the studies. In addition, researchers using the data may apply other inclusion and exclusion criteria for their research goals and often these criteria result in non-random participant exclusions.<sup>3</sup>



[1 Ensuring the Best Use of Data: The Adolescent Brain Cognitive Development Study](#)  
[2 Advancing high quality longitudinal data collection: Implications for the HEALTHy Brain and Child Development \(HBCD\) Study design and recruitment](#)  
[3 Limits to the generalizability of resting-state functional magnetic resonance imaging studies of youth: An examination of ABCD Study<sup>®</sup> baseline data](#)


[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) [1 of 2](#)

## 1.6 How representative are the ABCD and HBCD samples? (2/2)

### How representative are the ABCD and HBCD samples? (2/2)

Researchers should consider these qualifiers when interpreting their findings and describing the generalizability of the results, addressing any limitations,<sup>4,5</sup> to avoid misinterpretation of results.



4 [Why weight? Analytic approaches for large-scale population neuroscience data](#)  
5 [A Guide for Population-based Analysis of the Adolescent Brain Cognitive Development \(ABCD\) Study Baseline Data](#)

[Go Back](#) [Continue](#)


[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) [1 of 6](#)

## 1.7 What is the NBDC Biospecimen Access Program?

### What is the NBDC Biospecimen Access Program?

The NBDC Biospecimen Access Program provides a platform for the research community to access biospecimens collected from the NIH Brain Development Cohorts. Biospecimens collected from the ABCD Study<sup>®</sup> are available through a competitive [X01 resources access award](#). Biospecimens collected from the HBCD Study are not currently available.

If you are interested in using ABCD Study<sup>®</sup> biospecimens in your research, please visit the [NBDC Biospecimen Access Program website](#) for more information about the ABCD Study<sup>®</sup>, the available resources, the process for applying to the X01 Resource Access Program, and Frequently Asked Questions. The [NBDC portal](#) has tools researchers need to [explore the available biospecimens](#) and plan their research. The ["Requesting Biospecimens" tab](#) will help guide you through the process.



[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) [1 of 6](#)

Notes:




## 2. Ethical Principles

### 2.1 Ethical principles

**Ethical principles**

Data from the ABCD Study® and HBCD Study come from participants enrolled at research sites across the country who have entrusted us with their confidential information.

A pair of golden scales of justice is centered in the image. The background is a vibrant, abstract collage of colors including red, blue, green, yellow, and purple. The scales are positioned over a faint, stylized profile of a human head.

Go Back Continue

9 of 62

Notes:


## 2.2 Ethical principles and guidelines: The Belmont Report

### Ethical principles and guidelines: *The Belmont Report*

The **National Research Act of 1974 (PL 93-348)** led to the formation of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

One of the charges of the commission was to delineate ethical principles governing the conduct of biomedical and behavioral research. The commission published its guidance, *The Belmont Report*, in 1979.

[You can view the full \*Belmont Report\* here.](#)



Go Back Continue


Introduction **Ethical Principles** Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 10 of 12

Notes:

## 2.3 Ethical principles and guidelines

### Ethical principles and guidelines

Authorized users of NBDC data and biospecimens should be aware of the three basic ethical principles of human subjects research when working with the data as described in the [Belmont Report](#). These principles were originally established for research involving direct interaction with participants, yet they remain essential for establishing ethical guidelines governing secondary data analysis involving human participants.



Select each principle to read more before continuing.

Respect for persons Beneficence Justice

Go Back Continue

Introduction **Ethical Principles** Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 11 of 12

## Notes:

### justice (Slide Layer)

#### Justice

- Justice demands that the burdens, harms, and benefits of research are distributed fairly.
- An injustice occurs when someone does not receive a benefit to which they are entitled.
- In research involving human participants, researchers must not systematically select participants from certain groups for reasons other than those related to the problem being studied.
- Researchers must ensure that the harms and burdens of research participation do not fall disproportionately on people who are unlikely to experience any direct or long-term benefit from participation. This could further exacerbate health disparities among vulnerable populations.


[Go Back](#) [Continue](#)

Introduction **Ethical Principles** Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 1 of 6

### beneficence (Slide Layer)

#### Beneficence

- While all research studies carry some potential risk, researchers should always endeavor to minimize this risk. Two complementary principles underlie beneficence:
  - Minimize harm (physical, psychological, social, or economic)
  - Maximize possible benefits



[Go Back](#) [Continue](#)

Introduction **Ethical Principles** Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 1 of 6

## respect (Slide Layer)

### Respect for persons

- Researchers must respect participants' privacy, autonomy, and their expectations about how their data are used.
- Participants from vulnerable populations, such as children, are entitled to additional protections.
- Individuals who experience economic, social, or educational disadvantage can be susceptible to pressures to participate in research and are entitled to additional protections. Criteria for determining if an individual falls into one of these categories can vary depending on the context of the research. Institutional Review Boards are encouraged to assess potential vulnerabilities in a research project and ensure that appropriate protections are in place.

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 1 of 12

## 2.4 Bioethical standards

### Bioethical standards

This example from Johns Hopkins University highlights the shift in bioethical standards in the United States from the 1950s to today.

Select each button to learn what was happening in the 1950s compared to now.

	1950s	Current Practices
Informed Consent		
Collecting Patient Samples for Research		
Using Patient Cells for Research		
Medical Records Privacy		
Segregation		

[Go Back](#) [Continue](#)

Table source: [Understanding the Highest Bioethical Standards](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 12 of 12

Notes:

## Informed consent (Slide Layer)

### Bioethical standards

This example from Johns Hopkins University highlights the shift in bioethical standards in the United States from the 1950s to today.

Select each button to learn what was happening in the 1950s compared to now.

	1950s	Current Practices
<b>Informed Consent</b>	There was no established practice for informing or obtaining consent from cell or tissue donors.	Johns Hopkins and other medical research centers maintain strict patient consent processes for those who donate tissue and cellular materials for research.
Collecting Patient Samples for Research		
Using Patient Cells for Research		
Medical Records Privacy		
Segregation		

Go Back Continue

Table source: [Unholding the Highest Bioethical Standards](#)

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 1 of 8

## Collecting samples (Slide Layer)

### Bioethical standards

This example from Johns Hopkins University highlights the shift in bioethical standards in the United States from the 1950s to today.

Select each button to learn what was happening in the 1950s compared to now.

	1950s	Current Practices
Informed Consent		
<b>Collecting Patient Samples for Research</b>	It was common practice at Johns Hopkins to collect tissue samples from cervical cancer patients without any oversight of an Institutional Review Board.	Today, any request for samples for research purposes would fall under regulatory and legal standards, and the oversight of an Institutional Review Board (IRB).
Using Patient Cells for Research		
Medical Records Privacy		
Segregation		

Go Back Continue

Table source: [Unholding the Highest Bioethical Standards](#)

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 1 of 8

## Using cells (Slide Layer)

### Bioethical standards

This example from Johns Hopkins University highlights the shift in bioethical standards in the United States from the 1950s to today.

Select each button to learn what was happening in the 1950s compared to now.

	1950s	Current Practices
Informed Consent	There were no local or national regulations on the use of cells in research.	It is standard practice to have an IRB examine every research study involving human participants before it is approved. IRBs uphold strict standards of informed consent for all potential participants in human research involving cell or tissue donation.
Collecting Patient Samples for Research		
Using Patient Cells for Research		
Medical Records Privacy		
Segregation		

Go Back Continue

Table source: [Unholding the Highest Bioethical Standards](#)

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 1 of 6

## Med records (Slide Layer)

### Bioethical standards

This example from Johns Hopkins University highlights the shift in bioethical standards in the United States from the 1950s to today.

Select each button to learn what was happening in the 1950s compared to now.

	1950s	Current Practices
Informed Consent	Patients had no right to see or retain a copy of their medical records. No state or federal laws prohibited the sharing of medical record information in connection with research.	Today, patients have a right to see and have a copy of their medical records. Both state and federal laws regulate patient consent and the use and sharing of medical record information.
Collecting Patient Samples for Research		
Using Patient Cells for Research		
Medical Records Privacy		
Segregation		

Go Back Continue

Table source: [Unholding the Highest Bioethical Standards](#)

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 1 of 6

## Segregation (Slide Layer)

**Bioethical standards** This example from Johns Hopkins University highlights the shift in bioethical standards in the United States from the 1950s to today.

Select each button to learn what was happening in the 1950s compared to now.

	1950s	Current Practices
Informed Consent		
Collecting Patient Samples for Research		
Using Patient Cells for Research		
Medical Records Privacy		
Segregation	Very few leading hospitals treated Black patients. Johns Hopkins hospital was an exception. However, Black patients were treated in segregated wards at this time, and for many years thereafter.	Johns Hopkins began desegregating in the 1950s with full integration of ward services in Surgery in 1959. By 1973, all inpatient services were desegregated.

Table source: Upholding the Highest Bioethical Standards

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 13 of 62

Go Back Continue

## 3. Responsible Use of ABCD Data

### 3.1 Responsible Use of NBDC Data and Biospecimens

## Responsible Use of NBDC Data and Biospecimens

Alongside expanding opportunities for accessing complex datasets is the responsibility for scientifically rigorous data analysis and interpretation.

The following topics are reviewed in this section:

- I. Historical and contemporary science
- II. Use of contextualizing variables in statistical models
- III. Caution when developing biologically deterministic explanations

Go Back Continue

13 of 62

Notes:

### 3.2 Historical and contemporary science (1/9)

## Historical and contemporary science (1/9)

### Tuskegee Syphilis Experiment



The Tuskegee Syphilis Experiment was an observational study that began in the early 1930s and continued for 40 years. The purpose was to examine the natural course of untreated syphilis in Black men. The men were told they would receive free healthcare from the United States government in return for participating. They did not. All three ethical principles outlined in the Belmont Report were violated:

- *Respect for persons* – Participants were not fully informed about the study and could therefore not make autonomous decisions.
- *Beneficence* – Participants were harmed because no treatment was offered even after treatments became available.
- *Justice* – Only Black men were selected to participate, and burdens were unduly felt by this group.

Photo source: [CDC: The Tuskegee Timeline](#)

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) [of 10](#)

Notes:

### 3.3 Historical and contemporary science (2/9)

## Historical and contemporary science (2/9)

### Henrietta Lacks



Henrietta Lacks by Kadir Nelson (2017, Oil on linen). Collection of the Smithsonian National Portrait Gallery and National Museum of African American History & Culture. Gift from Kadir Nelson and the JKBN Group, LLC.

- In the early 1950s, [Henrietta Lacks](#) became a patient at Johns Hopkins University for treatment of cervical cancer. At the time, Johns Hopkins was one of just a few hospitals that treated Black patients.
- The standard protocol included extracting and harvesting cancer cells. Most cells quickly died, but Ms. Lacks' cells did not. They doubled every 24 hours.
- Soon, Ms. Lacks was unknowingly donating her cells, known as *HeLa* cells, to researchers around the world. Ms. Lacks never knew the cells existed, and her family didn't learn about them until 20 years after her death.
- In 2013, more than 60 years after Ms. Lacks' death, Johns Hopkins University worked with the National Institutes of Health (NIH) and the family of Ms. Lacks to institute a policy requiring that researchers obtain permission to use the *HeLa* cell line in NIH-funded research. The overseeing committee now includes two members of Ms. Lacks' family.

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 6 of 8

Notes:

### 3.4 Historical and contemporary science (3/9)

## Historical and contemporary science (3/9)

### American Indian and Alaska Native Communities



"Positively no beer sold to Indians" mid 1940s bar sign. Source: Wikimedia Commons

- Beginning in the 15th century when Europeans introduced AI/AN communities to alcohol, alcoholism rates have increased relative to other groups.
- This led to the flawed belief ("firewater" myth) that AI/AN individuals are unable to tolerate alcohol because of genetic "inferiority".
- The "firewater" myth, popularized over many decades, discounts the multigenerational impact of trauma and stress brought on by European colonization.

Go Back Continue


Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 6 of 8

Notes:

### 3.5 Historical and contemporary science (4/9)

## Historical and contemporary science (4/9)

### The Havasupai Case



Between 1990 and 1994, Arizona State University (ASU) researchers collected DNA samples from approximately 400 Havasupai Tribe members as part of the Diabetes Project, with the objective of understanding the high incidence of type 2 diabetes among them.<sup>1</sup> ASU researchers recruited tribal members, informing tribal leaders that the samples would be used to study genetic risk factors for diabetes.

<sup>1</sup>Garrison 2012

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 7 of 8

Notes:

### 3.6 Historical and contemporary science (5/9)

## Historical and contemporary science (5/9)

### The Havasupai Case



When subsequent studies found no genetic link to diabetes, the samples were used in unrelated research, including studies about:

- Schizophrenia
- Population relatedness
- Ancestral migration

Though the consent forms mentioned research on “behavioral/medical problems,” they were in English instead of the participant’s primary language, and these other uses were not mentioned during recruitment.<sup>2</sup>

<sup>2</sup> [Hart, S. & Sobraske, K. \(2003\)](#)

[Go Back](#) [Continue](#)

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 18 of 20

Notes:

### 3.7 Historical and contemporary science (6/9)

## Historical and contemporary science (6/9)

### The Havasupai Case



Tribal members asserted that they would not have consented to such research had they been properly informed because of:

- Havasupai beliefs around mental illness and population relatedness
- Challenges to Havasupai origin beliefs, undermining the tribe’s sovereignty over their ancestral home
- Unauthorized access to their medical records, heightening mistrust

[Go Back](#) [Continue](#)

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 19 of 20

Notes:

### 3.8 Historical and contemporary science (7/9)

## Historical and contemporary science (7/9)

### The Havasupai Case



This breach of trust sparked significant repercussions, as many Native Americans view DNA as integral to their personhood, contrasting with prevailing United States research norms treating DNA as institutional property ([Washington University v. Catalona 2007](#)). In April 2010, the Havasupai Tribe v. Arizona Board of Regents case reached a settlement in the tribe's favor, which included the return of the tribe's DNA samples. This was incredibly meaningful to the tribe, as a Hopi geneticist put so eloquently:

*To us, any part of ourselves is sacred. Scientists say it's just DNA. For an Indian, it is not just DNA, it's part of a person, it is sacred, with deep religious significance. It is part of the essence of a person.*  
-Dr. Frank Dukepoo

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 10 of 10


Notes:

### 3.9 Historical and contemporary science (8/9)

## Historical and contemporary science (8/9)

Understanding the roots of health disparities

Understanding the roots of health disparities is a critical step in finding solutions to eliminate them. For example, the practice of redlining provides historical context for considering how some policies, practices, and beliefs may contribute to health outcomes.



Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 22 of 23

Notes:

### 3.10 Historical and contemporary science (9/9)

## Historical and contemporary science (9/9)

Neighborhood segregation

- Redlining maps were first created in 1935 under the [New Deal](#) by the [Homeowners Loan Corporation](#) to categorize neighborhoods according to “level of security risk.”
- “Type D” neighborhoods, delineated by a red line, were associated with the greatest “security risk” and were denied mortgage loans. These neighborhoods were often populated by Black residents.
- Redlining resulted in denial of goods and services (e.g., housing, financial services, healthcare) that could have long-term, even generational, consequences.


Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 22 of 23

Notes:

### 3.11 Responsible Data Use (1/5)

## Responsible Data Use (1/5)



It is the responsibility of all researchers to analyze and use data wisely, ethically, and with an understanding of the history of science.

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) [24 of 24](#)

### 3.12 Responsible Data Use (2/5)

## Responsible Data Use (2/5)

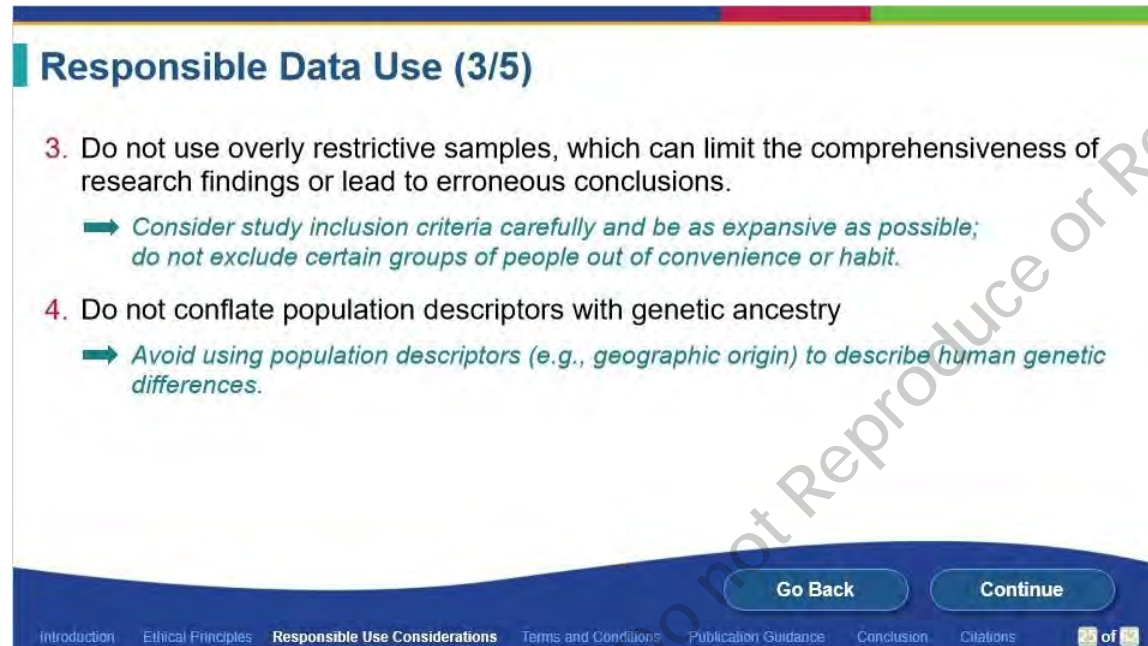
1. Understand the people whose lives form the basis of your research data.
2. Understand the limitations of techniques, instruments, data, measures, or methods, which may lead to inaccurate or incomplete interpretations of research findings.
  - ➔ *Address instrumentation limitations in methods and discussion sections of your manuscript, and acknowledge limitations in data or measures that may impact conclusions drawn from your analyses.*
  - ➔ *Attend to whether data missingness is an issue for measures under consideration. Differential missingness by demographic subgroups could impact how the data are analyzed and interpreted. This is especially important for studies with longitudinal designs.*

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) [24 of 24](#)

Notes:

### 3.13 Responsible Data Use (3/5)



The screenshot shows a presentation slide with a blue header and a white body. The title is 'Responsible Data Use (3/5)'. There are two main points, each with a sub-point. The first point is '3. Do not use overly restrictive samples, which can limit the comprehensiveness of research findings or lead to erroneous conclusions.' The sub-point is 'Consider study inclusion criteria carefully and be as expansive as possible; do not exclude certain groups of people out of convenience or habit.' The second point is '4. Do not conflate population descriptors with genetic ancestry.' The sub-point is 'Avoid using population descriptors (e.g., geographic origin) to describe human genetic differences.' At the bottom, there are two buttons: 'Go Back' and 'Continue'. A navigation bar at the very bottom shows the current slide is 3 of 5, with links for Introduction, Ethical Principles, Responsible Use Considerations, Terms and Conditions, Publication Guidance, Conclusion, and Citations.

## Responsible Data Use (3/5)

3. Do not use overly restrictive samples, which can limit the comprehensiveness of research findings or lead to erroneous conclusions.
  - ➔ Consider study inclusion criteria carefully and be as expansive as possible; do not exclude certain groups of people out of convenience or habit.
4. Do not conflate population descriptors with genetic ancestry
  - ➔ Avoid using population descriptors (e.g., geographic origin) to describe human genetic differences.

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 3 of 5

Notes:

### 3.14 Responsible Data Use (4/5)

## Responsible Data Use (4/5)

5. Use objective language.
  - ➔ *Use language that is free of bias.*
6. Properly contextualize (e.g., environmental factors) and do not overgeneralize findings, which could lead others to incorrectly interpret your study's results.
  - ➔ *Integrate contextualizing variables in statistical models that elucidate associated factors that may be driving observed between-group differences in outcomes. If appropriate contextual variables are not available, acknowledge those unknowns as limitations.*
  - ➔ *Consider how your research might be misinterpreted to the detriment of others; use precise language to describe your study's findings.*

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 26 of 32

Notes:

### 3.15 Responsible Data Use (5/5)

## Responsible Data Use (5/5)

Additional considerations for substance use research



Select each recommendation to read more before continuing.

1. Are you using "person first" language?
2. Are you using language that reflects accurate, science-based understanding of substance use?

Taken from, [Words Matter - Terms to Use and Avoid When Talking About Addiction](#) and [Language Matters When Discussing Substance Use](#)

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 27 of 32

Notes:

### 3.13.1 (Slide Layer)

**Responsible Data Use (5/5)**  
Additional considerations for substance use research



**1. Are you using “person first” language?**

Person first language (for example, reference to “a person with substance use disorder”) suggests that the person has a problem that can be addressed. By contrast, calling someone a “drug abuser” implies that the person is the problem.

Taken from [Words Matter - Terms to Use and Avoid When Talking About Addiction](#) and [Language Matters When Discussing Substance Use](#)

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 7 of 8

### 3.13.2 (Slide Layer)

**Responsible Data Use (5/5)**  
Additional considerations for substance use research



**2. Are you using language that reflects accurate, science-based understanding of substance use?**

Using language that is not science-based can elicit negative associations and punitive attitudes (e.g., “dirty” urine; “addict”).

Taken from [Words Matter - Terms to Use and Avoid When Talking About Addiction](#) and [Language Matters When Discussing Substance Use](#)

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 7 of 8

### 3.16 Contextualizing Variables (1/2)

## Contextualizing Variables (1/2)

### I. Incorporating appropriate variables into predictive models is good scientific practice

Researchers should be aware of assumptions they are making when including demographic variables in their models. For example, income and education are both related to socioeconomic status but there can be different underlying mechanisms (resource deprivation versus social capital) and, if measured, should be explicitly stated by researchers.

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 2 of 3

Notes:


### 3.17 Contextualizing Variables (2/2)

## Contextualizing Variables (2/2)

### II. Statistical models must be conceptually and theoretically grounded

Researchers should:

- Avoid controlling for demographic variables if they could provide context for other explanatory variables in the model
- Build comprehensive models that incorporate possible moderating or mediating variables so that social constructs are not included as independent variables in isolation
- Consider the possibility of unmeasured effects that could explain variability in the model



[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 3 of 3

### Consider the possibility Bullet 3 (Slide Layer)

## Contextualizing Variables (2/2)

II. Statistical models must be conceptually and theoretically grounded

Researcher

- Avoid variables that are not independent variables in isolation
- Build possible models that consider the possibility of unmeasured effects that could explain variability in the model

NBDC datasets may not include all possible variables that could be impacting measured outcomes. See SM.4 Example in Sensitivity Analysis for Unmeasured Confounding in Dick et al. (2021): [Meaningful associations in the adolescent brain cognitive development study](#) for discussion of unmeasured confounds and example analysis.

Go Back Continue


Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 44 of 44

### 3.18 Caution in drawing biologically deterministic interpretations (1/2)

## Caution in drawing biologically deterministic interpretations (1/2)

Most health outcomes result from a combination of biological and non-biological factors that may be modifiable. Biologically deterministic interpretations often assume fixed outcomes that do not interact with broader contextual factors, such as environment or development.

Research that is not appropriately contextualized at the outset may lead readers to draw unwarranted conclusions from observed differences that fail to consider the broader context for developmental change and environmental adaptation.



Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 44 of 44

### 3.19 Caution in drawing biologically deterministic interpretations (2/2)

**Caution in drawing biologically deterministic interpretations (2/2)**  
Four ways to avoid deterministic interpretations

Youths are continuously adapting to their environments. Often, deterministic claims may not be appropriate on the basis of a single time point using cross-sectional observational data or on the basis of repeated measurements within a circumscribed developmental period.

Select each button to learn about four ways to avoid deterministic interpretations.

- 1
- 2
- 3
- 4

(Adapted from Simmons et al. 2021 and Nketia et al. 2021)

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 21 of 22

Notes:

#### Layer 1 (Slide Layer)

**Caution in drawing biologically deterministic interpretations (2/2)**  
Four ways to avoid deterministic interpretations

Youths are continuously adapting to their environments. Often, deterministic claims may not be appropriate on the basis of a single time point using cross-sectional observational data or on the basis of repeated measurements within a circumscribed developmental period.

Select each button to learn about four ways to avoid deterministic interpretations.

- 1  
Consider the changing context in which development occurs, such as neighborhood characteristics, school environment, and peer and family relationships.
- 2
- 3
- 4

(Adapted from Simmons et al. 2021 and Nketia et al. 2021)

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 21 of 22

## Layer 2 (Slide Layer)

### Caution in drawing biologically deterministic interpretations (2/2)

#### Four ways to avoid deterministic interpretations

Youths are continuously adapting to their environments. Often, deterministic claims may not be appropriate on the basis of a single time point using cross-sectional observational data or on the basis of repeated measurements within a circumscribed developmental period.

**Select each button to learn about four ways to avoid deterministic interpretations.**

- 1
- 2
- 3
- 4

Consider unmeasured contextual factors when examining developmental trajectories, such as environmental factors or neighborhood characteristics.

(Adapted from Simmons et al. 2021 and Nketia et al. 2021)

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 11 of 12

## Layer 3 (Slide Layer)

### Caution in drawing biologically deterministic interpretations (2/2)

#### Four ways to avoid deterministic interpretations

Youths are continuously adapting to their environments. Often, deterministic claims may not be appropriate on the basis of a single time point using cross-sectional observational data or on the basis of repeated measurements within a circumscribed developmental period.

**Select each button to learn about four ways to avoid deterministic interpretations.**

- 1
- 2
- 3
- 4

Consider individual responses to adverse experiences as reflections of dynamic, environmental adaptations, rather than fixed outcomes.

(Adapted from Simmons et al. 2021 and Nketia et al. 2021)

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 11 of 12

## Layer 4 (Slide Layer)

### Caution in drawing biologically deterministic interpretations (2/2)

#### Four ways to avoid deterministic interpretations

Youths are continuously adapting to their environments. Often, deterministic claims may not be appropriate on the basis of a single time point using cross-sectional observational data or on the basis of repeated measurements within a circumscribed developmental period.

**Select each button to learn about four ways to avoid deterministic interpretations.**

- 1
- 2
- 3
- 4

Partner with members of the community with similar lived experiences as participants involved in the research (e.g., community-based organizations, neighborhood groups, patients, advocates) to understand the dynamics of the context in which the research is taking place.

(Adapted from Simmons et al. 2021 and Nketia et al. 2021)


Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 11 of 12

### 3.20 Example Case 1

### Example Case 1

Select "Points to consider" to read more before continuing.



**CONSIDER THIS USE CASE:**

A group of researchers seek to determine how prenatal cannabis exposure affects children's long-term development. Researchers were provided access to data from a longitudinal, observational cohort study of 7000 enrolled mother/child dyads. After limiting their analysis to individuals with measures from the prenatal period and visit 12 (child ages 4-6), the sample included 2200 mother/child dyads. Prenatal cannabis exposure was defined by a positive urine drug screen for cannabis at the time of urine collection in the 2nd or 3rd trimester (n=125), one of several sources of exposure information. The developmental outcome selected was the measure 'Dimensional Change Card Sort' from the NIH Toolbox Early Childhood Cognition Battery. Researchers conducted statistical analyses, using the remaining 2075 children as a comparison group, to estimate associations between prenatal cannabis exposure and outcomes on the cognitive tasks. After adjusting for other prenatal substance exposures, demographic, and maternal health characteristics, researchers found no significant differences in the average outcomes on the cognitive measure between the groups at ages 4 or 6 and concluded that prenatal cannabis exposure does not negatively affect childhood cognition.

Points to consider

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 12 of 12

Notes:

## layer (Slide Layer)

### Example Case 1

**POINTS TO CONSIDER:**

1. The researchers examined a single source of substance exposure at only one time point. Instead, they could have used all available sources of exposure information (including the pregnant participant's self-report at different weeks of gestation and additional matrices - e.g. hair, nails,) across gestation to obtain a more accurate assessment of exposure.
  - [Validity of Self-Reported Cannabis Use Among Pregnant Females in Northern California](#)
  - [Patterns of Prenatal Alcohol Use That Predict Infant Growth and Development](#)
2. The researchers appropriately controlled for substance exposures other than cannabis. Among people using at least one substance during pregnancy, polysubstance use is common. Therefore, it is important to account for other substance exposure that may influence the outcome of interest.
  - [Polysubstance Use in Pregnancy: Surveillance, Interventions, and Next Steps](#)
3. The researchers used cognitive data from a single timepoint (ages 4-6) and from a very narrowly defined measure to make broad conclusions about childhood cognition. Instead, the researchers could have been more careful to limit the interpretations of their findings to the specific domain and age range that was analyzed so as to minimize unwarranted assumptions, implications, or conclusions when communicating findings.
4. The researchers did not consider cohort attrition in their models. This means attending to selection bias, as the analytic sample (n=2200) was only 31% of the full cohort, and individuals with missing data or who were lost to follow up may differ from people in the full sample with respect to the exposure and outcome, leading to systematic bias in the effect estimate. Researchers should consider inverse probability censoring weights or other techniques to mitigate selection bias.
  - [Meaningful Associations in the Adolescent Brain Cognitive Development Study](#)


[Go Back](#) [Continue](#)

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 12 of 15

### 3.21 Example Case 2

### Example Case 2

Select "Points to consider" to read more before continuing.



**CONSIDER THIS USE CASE:**  
Investigators are interested in how biological sex impacts early brain development, so they compare brain volumes in boys and girls (ages 9 – 10 years). They download preprocessed MRI data from a single time point from all children included in the second data release of a large longitudinal cohort study of child development. They find that boys have larger volumes in the parietal brain region than girls and conclude that these volume differences indicate that young boys are likely advantaged at numeracy.

[Points to consider](#)

[Go Back](#) [Continue](#)

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 13 of 15

Notes:

## layer (Slide Layer)

### Example Case 2

**POINTS TO CONSIDER:**

1. The researchers could have controlled for common factors that can co-vary or confound their variables of interest. The researchers did not account for demographic characteristics, total brain volume, motion artifacts, or other potential confounding factors that could impact measurements of regional brain volumes. The data releases for ABCD and HBCD include a variety of neuroimaging and non-neuroimaging data. Researchers are strongly encouraged to become familiar with the datasets, processing pipelines, and quality assurance measures to ensure that data are selected and analyzed appropriately.
  - [ABCD Data Documentation \(ABCD Wiki\)](#)
  - [HBCD Data Release Documentation](#)
2. The researchers examined brain development at only one time point, and did not account for age effects and their interactions. Brains of children between 9 and 10 years of age develop rapidly, and developmental trajectories can be non-linear. On average, young males and females have different growth patterns that researchers should account for in their analyses. In addition, researchers did not include age in the model, and we do not know whether there were any sex differences in age at assessment. If more boys were older, this could account for sex differences in brain volume.
  - [Neuroethics beyond genetics](#)
  - [Best practices in data analysis and sharing in neuroimaging using MRI](#)

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 33 of 36

## layer 2 (Slide Layer)

### Example Case 2

**POINTS TO CONSIDER:**

3. The researchers overinterpreted the implications of their neuroimaging findings. Brain differences between individuals or groups do not necessarily cause or correlate with behavioral differences, such as numeracy at a certain age.
  - [Brain charts for the human lifespan](#)
  - [Developmental trajectories during adolescence in males and females: A cross-species understanding of underlying brain changes](#)
4. The researchers should understand the strengths and limitations of the dataset and processing pipelines. Researchers should be careful to acknowledge the specific version of the data release they are using and pipelines used to process the data. Imaging technology is changing rapidly, and processing pipelines can improve over time. Therefore, data in the next or previous release might not be entirely comparable, e.g., segmentation of regions of interest from the structural data may change over time as more data become available or as technology changes.
  - [Limits to the generalizability of resting-state functional magnetic resonance imaging studies of youth: An examination of ABCD Study® baseline data](#)
  - [Effects of different intracranial volume correction methods on univariate sex differences in grey matter volume and multivariate sex prediction](#)

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 34 of 36

### 3.22 Manuscript preparation

**Manuscript preparation**  
Recommended considerations when preparing a manuscript

- What is your reason for analyzing data stratified by sample population?
- Have you acknowledged any potential limitations in measures/constructs (known or suspected)?
- Have you contextualized variables?
- Have you limited the use of deterministic language (especially important for developmental studies)?
- If demographic variables were used as covariates or for sample characteristic reporting, were they appropriately reported and are limitations of such reporting addressed?
- If your findings have shown significant differences between groups, describe how your data will inform the larger effort to improve health.

Go Back Continue

Introduction Ethical Principles **Responsible Use Considerations** Terms and Conditions Publication Guidance Conclusion Citations 14 of 15

Notes:

## 4. ABCD Study Data Use Terms and Conditions


### 4.1 NBDC data use terms and conditions (1/4)

**NBDC data use terms and conditions (1/4)**  
Gaining access to NBDC study data

The NBDC Data Hub is a data resource for the research community to access multi-modal data collected from the ABCD and HBCD Studies.

In order to gain access to the data, you and your institution must sign a data use certification (DUC) agreeing to terms and conditions for responsible data use.

These are summarized in the following slides.



Go Back Continue

35 of 62

Notes:

## 4.2 NBDC data use terms and conditions (2/4)

### NBDC data use terms and conditions (2/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 6 through 10.

- 1 Data access, use, and purpose
- 2 Restrictions on data sharing and transfer
- 3 Data destruction and retention
- 4 Data security, incident response, and IT safeguards
- 5 Responsible use and training requirements

[Go Back](#) [Continue](#)

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 26 of 30

### 1 (Slide Layer)

### NBDC data use terms and conditions (2/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 6 through 10.

- 1 Data access, use, and purpose
- 2 Restrictions on data sharing and transfer
- 3 Data destruction and retention
- 4 Data security, incident response, and IT safeguards
- 5 Responsible use and training requirements

**1. Data access, use, and purpose**

*Data must be used strictly for approved research, scholarship, or teaching as outlined in the Research Data Use Statement. Access is time-limited (maximum of one year), and continued use requires renewal of the Data Use Certification (DUC). Recipients must ensure compliance with all relevant data sharing policies throughout the access period.*

*See DUC Terms and Conditions: 3, 25, 26*

[Go Back](#) [Continue](#)

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 26 of 30

## 2 (Slide Layer)

### NBDC data use terms and conditions (2/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 6 through 10.

1	Data access, use, and purpose
2	Restrictions on data sharing and transfer
3	Data destruction and retention
4	Data security, incident response, and IT safeguards
5	Responsible use and training requirements

#### 2. Restrictions on data sharing and transfer

*Recipients are not permitted to transfer data to unauthorized users or third-party platforms, including commercial tools like large language models (e.g., ChatGPT). If recipients move institutions, they must submit a new DUC. Data may only be shared with authorized collaborators under specified conditions.*

1. Recipients may share data with other authorized researchers at the same institution.
2. Recipients may share data with authorized researchers from a different institution only through a

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 1 of 1

## 3 (Slide Layer)

### NBDC data use terms and conditions (2/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 6 through 10.

1	Data access, use, and purpose
2	Restrictions on data sharing and transfer
3	Data destruction and retention
4	Data security, incident response, and IT safeguards
5	Responsible use and training requirements

#### 3. Data destruction and retention

*Downloaded data must be permanently deleted from all local or cloud-based machines once the project ends or the DUC expires, whichever comes first. Retention is only allowed under specific legal or policy requirements, and recipients remain accountable for safeguarding retained data. Recipients are encouraged to avoid local data downloads and to download data to a secure sharing mechanism supported by the NBDC Data Hub, when it becomes available.*

*See DUC Terms and Conditions: 12, 13.*

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 1 of 1

## 4 (Slide Layer)

### NBDC data use terms and conditions (2/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 6 through 10.

1	Data access, use, and purpose
2	Restrictions on data sharing and transfer
3	Data destruction and retention
4	Data security, incident response, and IT safeguards
5	Responsible use and training requirements

#### 4. Data security, incident response, and IT safeguards

*Recipients must maintain high IT security standards to protect sensitive NIH data. In the event of a security incident or data breach, recipients must notify the NIH Incident Response Team, the NBDC Data Access Committee (DAC) at [nbdc@mail.nih.gov](mailto:nbdc@mail.nih.gov), and the NIH Office of Extramural Research Data Sharing Policy Implementation (OER/DSPI) Team at [DMI\\_OER@mail.nih.gov](mailto:DMI_OER@mail.nih.gov) within 24 hours and submit a detailed report within three business days. They must implement preventive and remedial measures and may be subject to additional investigations. Security measures include encryption, patch management, and access*

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) **[Terms and Conditions](#)** [Publication Guidance](#) [Conclusion](#) [Citations](#) 1 of 5

## 5 (Slide Layer)

### NBDC data use terms and conditions (2/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 6 through 10.

1	Data access, use, and purpose
2	Restrictions on data sharing and transfer
3	Data destruction and retention
4	Data security, incident response, and IT safeguards
5	Responsible use and training requirements

#### 5. Responsible use and training requirements

*Prior to data access, all users must complete a training module on responsible data and biospecimen use, passing with a minimum score of 90%. This ensures that recipients understand ethical standards and data use responsibilities. The training helps mitigate misuse and promotes compliance with NIH standards.*

*See DUC Terms and Conditions: 10*

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) **[Terms and Conditions](#)** [Publication Guidance](#) [Conclusion](#) [Citations](#) 1 of 5

### 4.3 NBDC data use terms and conditions (3/4)

**NBDC data use terms and conditions (3/4)**  
You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 11 through 15.

- 6 Confidentiality and de-identification
- 7 Ethical research conduct and special considerations for use of data from American Indian/ Alaska Native (AI/AN) individuals
- 8 Documentation and data context
- 9 Publication and reporting
- 10 Research transparency and reproducibility

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 17 of 20

Notes:

### 6 (Slide Layer)

**NBDC data use terms and conditions (3/4)**  
You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 11 through 15.

- 6 Confidentiality and de-identification
- 7 Ethical research conduct and special considerations for use of data from American Indian/ Alaska Native (AI/AN) individuals
- 8 Documentation and data context
- 9 Publication and reporting
- 10 Research transparency and reproducibility

**6. Confidentiality and de-identification**

*Recipients are prohibited from identifying individuals (or their relatives) or publishing data or derived data in a way that could lead to identification. To that end, Recipients agree to adhere to a minimum cell threshold of 10 in public reporting of data, including scientific publications and presentations. For any questions concerning whether derived data can aid in identification, IRB consultation is recommended to mitigate these risks. Recipients agree to notify the NIH at [nbdc@mail.nih.gov](mailto:nbdc@mail.nih.gov) as soon as possible if any identifying information is discovered. Additionally,*

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 17 of 20

## 7 (Slide Layer)

### NBDC data use terms and conditions (3/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 11 through 15.

- 6 Confidentiality and de-identification
- 7 Ethical research conduct and special considerations for use of data from American Indian/ Alaska Native (AI/AN) individuals
- 8 Documentation and data context
- 9 Publication and reporting
- 10 Research transparency and reproducibility

#### 7. Ethical research conduct and special considerations for use of data from American Indian/ Alaska Native (AI/AN) individuals

*Researchers must avoid using the data in ways that could promote stigma or harm vulnerable populations. Special guidelines are required for the ethical use and dissemination of findings involving American Indian/Alaska Native (AI/AN) communities. These measures are intended to respect tribal sovereignty and prevent misrepresentation. Recipients who intend to disseminate findings from analyses of AI/AN data separated out from other groups in presentations, pre-prints,*

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 11 of 15

## 8 (Slide Layer)

### NBDC data use terms and conditions (3/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 11 through 15.

- 6 Confidentiality and de-identification
- 7 Ethical research conduct and special considerations for use of data from American Indian/ Alaska Native (AI/AN) individuals
- 8 Documentation and data context
- 9 Publication and reporting
- 10 Research transparency and reproducibility

#### 8. Documentation and data context

*NBDC provides supporting documentation, including research protocols, questionnaires, and data notes, to help recipients properly understand and analyze the data. Recipients are expected to review these materials to ensure responsible use, particularly if unfamiliar with the original research context. This enhances the accuracy and reproducibility of subsequent analyses.*

*See DUC Terms and Conditions: 14*

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 11 of 15

## 9 (Slide Layer)

### NBDC data use terms and conditions (3/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 11 through 15.

- 6 Confidentiality and de-identification
- 7 Ethical research conduct and special considerations for use of data from American Indian/ Alaska Native (AI/AN) individuals
- 8 Documentation and data context
- 9 Publication and reporting
- 10 Research transparency and reproducibility

#### 9. Publication and reporting

*Any oral and written presentations, disclosures, or presentations resulting from analyses of NBDC data must be linked back to the source dataset with a Digital Object Identifier (DOI). Any publications resulting from NBDC data should be registered on the NBDC Data Hub once a DOI and/or PubMed ID is assigned to that publication. Recipients are encouraged to share computational methods, such as code or algorithms, to support open science practices. This ensures traceability and accountability in research outputs.*

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 11 of 15

## 10 (Slide Layer)

### NBDC data use terms and conditions (3/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to see items 11 through 15.

- 6 Confidentiality and de-identification
- 7 Ethical research conduct and special considerations for use of data from American Indian/ Alaska Native (AI/AN) individuals
- 8 Documentation and data context
- 9 Publication and reporting
- 10 Research transparency and reproducibility

#### 10. Research transparency and reproducibility

*Recipients are encouraged to register planned or exploratory analyses on open science platforms, such as [Open Science Framework](#), prior to conducting research. This practice supports scientific integrity and transparency, even if the research does not lead to publication. It also promotes reproducibility and trust within the research community.*

*See DUC Terms and Conditions: 15*

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 11 of 15

## 4.4 NBDC data use terms and conditions (4/4)

**NBDC data use terms and conditions (4/4)**  
You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to learn about publication guidance.

- 11 Institutional compliance
- 12 Legal disclaimers and liability
- 13 Accuracy of representations
- 14 Public disclosure and Privacy Act
- 15 DUC Amendments and Termination

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 28 of 32

Notes:

### 11 (Slide Layer)

**NBDC data use terms and conditions (4/4)**  
You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to learn about publication guidance.

- 11 Institutional compliance
- 12 Legal disclaimers and liability
- 13 Accuracy of representations
- 14 Public disclosure and Privacy Act
- 15 DUC Amendments and Termination

**11. Institutional compliance**

*Data use must align with institutional requirements, including IRB approval and an active Federalwide Assurance (FWA). Recipients must also comply with applicable federal, state, and local laws governing human subjects research. The DUC supplements, but does not override, these institutional and legal requirements.*

See DUC Terms and Conditions: 20

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 29 of 32

## 12 (Slide Layer)

### NBDC data use terms and conditions (4/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to learn about publication guidance.

- 11 Institutional compliance
- 12 Legal disclaimers and liability
- 13 Accuracy of representations
- 14 Public disclosure and Privacy Act
- 15 DUC Amendments and Termination

**12. Legal disclaimers and liability**

*NIH does not guarantee the accuracy or reliability of the data or tools provided and disclaims liability for research outcomes. Recipients accept responsibility for their actions under the agreement, and no party, including NIH, provides indemnification except where required by law. These clauses are standard in federal agreements to limit legal exposure.*

See DUC Terms and Conditions: 18, 19

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 12 of 15

## 13 (Slide Layer)

### NBDC data use terms and conditions (4/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to learn about publication guidance.

- 11 Institutional compliance
- 12 Legal disclaimers and liability
- 13 Accuracy of representations
- 14 Public disclosure and Privacy Act
- 15 DUC Amendments and Termination

**13. Accuracy of representations**

*Recipients certify that all information provided in the DUC accurate and truthful. This affirmation helps ensure the integrity of the agreement and the responsible use of data. Misrepresentation could result in compliance actions or termination.*

See DUC Terms and Conditions: 27

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 13 of 15

## 14 (Slide Layer)

### NBDC data use terms and conditions (4/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to learn about publication guidance.

- 11 Institutional compliance
- 12 Legal disclaimers and liability
- 13 Accuracy of representations
- 14 Public disclosure and Privacy Act
- 15 DUC Amendments and Termination

#### 14. Public disclosure and Privacy Act

*NIH and the NBDC Data Hub may publicly share limited information about data recipients, such as names, affiliations, and research topics, for transparency and reporting purposes. This is governed by the Privacy Act of 1974. Although submission of this information is voluntary, it is required to obtain data access.*

See DUC Terms and Conditions: 21, 22

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 4 of 4

## 15 (Slide Layer)

### NBDC data use terms and conditions (4/4)

You and your institution agree to adhere to NBDC data use terms and conditions.

Select each number for more information. Then, select Continue to learn about publication guidance.

- 11 Institutional compliance
- 12 Legal disclaimers and liability
- 13 Accuracy of representations
- 14 Public disclosure and Privacy Act
- 15 DUC Amendments and Termination

#### 15. DUC Amendments and Termination

*The DUC may be amended in writing by mutual agreement. Either party may terminate the agreement with notice, but the NIH may act more quickly if a breach occurs. Even after termination, certain obligations (e.g., confidentiality, data security) may remain in effect.*

See DUC Terms and Conditions: 23, 24

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 4 of 4

## 4.5 National Institute of Standards & Technology (NIST) Security Compliance

### National Institute of Standards & Technology (NIST) Security Compliance

Compliance with industry standards is essential for maintaining security, and meeting regulatory requirements.

Approved Users of NIH controlled-access data under the Genomic Data Sharing Policy systems must comply with [NIH Security Best Practices for Users of Controlled-Access Data](#) and maintain such data on institutional IT systems, cloud service providers, and/or third-party IT systems with security standards that meet or exceed [NIST SP 800-171](#) or the equivalent [ISO/IEC 27001/27002](#) standards. *Note that this policy applies to all controlled- access NIH Brain Development Cohorts (NBDC) data, not just genomic data.*

**Institutions with Plans of Action and Milestones (POAMs) to mitigate security risks will be considered compliant.**

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 10 of 10

Notes:

## 4.6 NIST security compliance attestation on the NBDC Platform

### NIST security compliance attestation on the NBDC Platform

You and your institution must attest to security compliance to access NBDC data.

**Investigator attestation:**

- By checking this box, I, as the PI requesting access to this data, attest that data will be secured, at a minimum, in accordance with [NIST SP 800-171](#) or the equivalent [ISO/IEC 27001/27002](#) standards as stipulated by the NIH Security Best Practices for Users of Controlled-Access Data. Institutions with Plans of Action and Milestones (POAMs) to mitigate security risks will be considered compliant.
- By checking this box, I attest that the cloud service provider and/or third-party IT system used for data analysis and/or storage will secure data, at a minimum, in accordance with [NIST SP 800-171](#) or the equivalent [ISO/IEC 27001/27002](#) standards as stipulated by the NIH Security Best Practices for Users of Controlled-Access Data.

**Institutional Signing Official Attestation:**

- By checking this box, I attest on behalf of this institution that all institutional IT systems, cloud service, providers, and/or third-party IT systems used for data analysis and/or storage will secure the requested data, at a minimum, in accordance with [NIST SP 800-171](#) or the equivalent [ISO/IEC 27001/27002](#) standards as stipulated by the NIH Security Best Practices for Users of Controlled-Access Data. Institutions with Plans of Action and Milestones (POAMs) to mitigate security risks will be considered compliant.

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 10 of 10


Notes:

#### 4.7 Data acknowledgements (1/6)

### Data acknowledgements (1/6)

When reporting results, creating a publication, or working on any other public disclosure involving ABCD Study® data, please use the ABCD word marks or logo marks shown below and on the following slides and refer to the [ABCD Trademarks and Service Guidance document](#) for appropriate use. Similar guidance for the HBCD Study will be available in the future.

Be sure to use the appropriate acknowledgement language to reference the ABCD Study® or the HBCD Study as the source of the original data. This language is documented in the Acknowledgements section of the Terms and Conditions of the Data Use Certification, and is reproduced on the following slides.



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

HEALTHY Brain and Child Development  
Babies • Brains • Bright Futures

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 41 of 62

#### 4.5 Layer 1 (Slide Layer)

### Data acknowledgements (1/6)

The ABCD Study® is supported by the National Institutes of Health and additional federal partners under award numbers U01DA041048, U01DA050989, U01DA051016, U01DA041022, U01DA051018, U01DA051037, U01DA050987, U01DA041174, U01DA041106, U01DA041117, U01DA041028, U01DA041134, U01DA050988, U01DA051039, U01DA041156, U01DA041025, U01DA041120, U01DA051038, U01DA041148, U01DA041093, U01DA041089, U24DA041123, U24DA041147. A full list of supporters is available at [Federal Partners - ABCD Study](#).

A listing of participating sites and a complete listing of the study investigators can be found at the [Complete ABCD Roster](#). ABCD consortium investigators designed and implemented the study and/or provided data but did not necessarily participate in the analysis or writing of this report. This manuscript reflects the views of the authors and may not reflect the opinions or views of the NIH or ABCD consortium investigators.

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 41 of 62

## 4.5 Layer 2 (Slide Layer)

### Data acknowledgements (1/6)

**Add the following sentence for a report that uses data from a versioned release.**  
The ABCD data repository grows and changes over time. The ABCD data used in this report came from [NBDC Digital Object Identifier (DOI)]. DOIs can be found at [DOI URL].

**Add the following sentence for a report that uses data from the fast track release.**  
The ABCD data repository grows and changes over time. The ABCD data used in this report came from the fast track data release. The raw data are available on the NBDC Data Sharing Platform.

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 41 of 62

## 4.5 Layer 3 (Slide Layer)

### Data acknowledgements (1/6)

**Add the following sentence for a report that uses data from an ABCD COVID-19 Data Release.**  
Additional support for this work was made possible from supplements to U24DA041123 and U24DA041147, the National Science Foundation (NSF 2028680), and Children and Screens: Institute of Digital Media and Child Development Inc. The ABCD data used in this report came from [NBDC Digital Object Identifier (DOI)]. DOIs can be found at [DOI URL].

**Add the following sentence for a report that uses linked external environmental data.**  
Additional support for this work was made possible from NIEHS R01-ES032295 and R01-ES031074.

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 41 of 62

#### 4.5 Layer 4 (Slide Layer)

### Data acknowledgements (1/6)

**Add the following sentence for a report that uses data from the ABCD-Social Development substudy.**

This project was supported by Award Number 2017-MU-CX-0044, awarded by the National Institute of Justice, Office of Justice Programs, U.S. Department of Justice with additional funding from the Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. The opinions, findings, and conclusions or recommendations expressed in this publication/program/exhibition are those of the author(s) and do not necessarily reflect those of the Department of Justice or the Department of Health and Human Services.

[Go Back](#) [Continue](#)

Introduction | Ethical Principles | Responsible Use Considerations | **Terms and Conditions** | Publication Guidance | Conclusion | Citations | 41 of 62

#### 4.8 Data acknowledgements (2/6)

### Data acknowledgements (2/6)

#### ABCD Study® Acknowledgements

Data used in the preparation of this article were obtained from the [Adolescent Brain Cognitive Development<sup>SM</sup> \(ABCD\) Study](#), held in the NIH Brain Development Cohorts Data Sharing Platform. This is a multisite, longitudinal study designed to recruit more than 10,000 children age 9-10 and follow them over 10 years into early adulthood

The ABCD Study® is supported by the National Institutes of Health and additional federal partners under award numbers U01DA041048, U01DA050989, U01DA051016, U01DA041022, U01DA051018, U01DA051037, U01DA050987, U01DA041174, U01DA041106, U01DA041117, U01DA041028, U01DA041134, U01DA050988, U01DA051039, U01DA041156, U01DA041025, U01DA041120, U01DA051038, U01DA041148, U01DA041093, U01DA041089, U24DA041123, U24DA041147. A full list of supporters is available at [Federal Partners – ABCD Study](#).

[Go Back](#) [Continue](#)

Introduction | Ethical Principles | Responsible Use Considerations | **Terms and Conditions** | Publication Guidance | Conclusion | Citations | 42 of 62

## 4.9 Data acknowledgements (3/6)

### Data acknowledgements (3/6)

**ABCD Study® Acknowledgements (Continued)**

**Add the following sentence for a report that uses data from a versioned release.**  
The ABCD dataset grows and changes over time. The ABCD data used in this report came from [NBDC Digital Object Identifier (DOI)]. DOIs can be found at [DOI URL].

**Add the following sentence for a report that uses data from the fast track release.**  
The ABCD dataset grows and changes over time. The ABCD data used in this report came from the fast-track data release. The raw data are available on the NBDC Data Sharing Platform.

**Add the following sentence for a report that uses data from an ABCD COVID-19 Data Release.**  
Additional support for this work was made possible from supplements to U24DA041123 and U24DA041147, the National Science Foundation (NSF 2028680), and Children and Screens: Institute of Digital Media and Child Development Inc. The ABCD data used in this report came from [NBDC Digital Object Identifier (DOI)]. DOIs can be found at [DOI URL].

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Credits](#) 43 of 62

## 4.10 Data acknowledgements (4/6)

### Data acknowledgements (4/6)

**ABCD Study® Acknowledgements (Continued)**

**Add the following sentence for a report that uses linked external environmental data.**  
Additional support for this work was made possible from NIEHS R01-ES032295 and R01-ES031074.

**Add the following sentence for a report that uses data from the ABCD-Social Development substudy.**  
This project was supported by Award Number 2017-MU-CX-0044, awarded by the National Institute of Justice, Office of Justice Programs, United States Department of Justice with additional funding from the Centers for Disease Control and Prevention, United States Department of Health and Human Services. The opinions, findings, and conclusions or recommendations expressed in this publication/program/exhibition are those of the author(s) and do not necessarily reflect those of the Department of Justice or the Department of Health and Human Services.

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Credits](#) 44 of 62

## 4.11 Data acknowledgements (5/6)

### Data acknowledgements (5/6)

#### HBCD Study Acknowledgements

[Data/Processes/Plans/Concepts, select as appropriate] used in the preparation of this article were obtained from the [HEALthy Brain and Child Development \(HBCD\) Study](#), held in the NIH Brain Development Cohorts Data Sharing Platform. This is a multisite, longitudinal study designed to recruit approximately 7,000 families and follow them from pregnancy to early childhood.

The HBCD Study is supported by the NIH and additional federal partners under award numbers U01DA055352, U01DA055353, U01DA055366, U01DA055365, U01DA055362, U01DA055342, U01DA055360, U01DA055350, U01DA055338, U01DA055355, U01DA055363, U01DA055349, U01DA055361, U01DA055316, U01DA055344, U01DA055322, U01DA055369, U01DA055358, U01DA055371, U01DA055359, U01DA055354, U01DA055370, U01DA055347, U01DA055357, U01DA055367, U24DA055325, U24DA055330. A full list of supporters is available at [Federal Partners-HBCD Study](#).

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 45 of 62

## 4.12 Data acknowledgements (6/6)

### Data acknowledgements (6/6)

#### HBCD Study Acknowledgements (Continued)

A full list of participating sites is available at [Study Sites-HBCD Study](#). HBCD Study Consortium investigators designed and implemented the study and/or provided data but did not necessarily participate in the analysis or writing of this report. This manuscript reflects the views of the authors and may not reflect the opinions or views of the NIH or the HBCD Study Consortium investigators.

**Add the following sentence for a report that uses data from a versioned data release.** The HBCD dataset grows and changes over time. The HBCD data used in this report came from NBDC Digital Object Identifier (DOI) <https://www.nbdc-datahub.org/hbcd-release-1-0>

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 46 of 62

## 4.13 NBDC Biospecimens Use Terms and Conditions

### NBDC Biospecimens Use Terms and Conditions

- ABCD Study® and HBCD Study biospecimens are held in NIH-sponsored biorepositories. Currently, only ABCD Study® biospecimens are available through the NBDC Biospecimen Access Program.
- You will need an approved NBDC DUC in order to search the portal at the individual participant level.
- If your X01 application is approved for access, you will need an approved NBDC DUC if you did not already provide one in order to identify data and register pending publications on the NBDC platform. In addition, you and your institution must agree to the terms in the X01 NOFO, Code of Conduct, Specimen and Data Transfer Agreement (SDTA), and Notice of Access Approval in order to receive specimens.

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations **Terms and Conditions** Publication Guidance Conclusion Citations 17 of 20

## 5. Publication Guidance

### 5.1 Publication Guidance

## Publication Guidance

Privacy, confidentiality, and anonymity

When reporting findings, researchers must strike a balance between including sufficient detail about their analyses and providing information that could potentially aid in the identification of study participants.

Select the image to enlarge.

Go Back Continue

48 of 62

Notes:

## 5.2 Preventing identification of participants

### Preventing identification of participants

Recommendations to prevent inadvertent identification of participants

Researchers should consider how public reporting of small n-size data (data with a relatively small number of observations or samples) could contribute to inadvertent identification of participants. According to [Best Practices for Determining Subgroup Size in Accountability Systems While Protecting Personally Identifiable Student Information](#) by the United States Department of Education's Institute of Education Sciences (IES), selecting a minimum n-size for reporting is a complex issue that involves important and difficult trade-offs.

- **High minimum n-sizes** can result in the exclusion of data for a substantial number of subgroups.
- **Low minimum n-sizes** can result in:
  - Misinterpretations, as when a change for a small number of participants results in a substantial change in the percentage of participants in one outcome category versus another
  - Large margin of error around the estimate for an outcome measure that could limit the utility of the outcome measure
  - Revealing personally identifiable information about individual participants in small subgroups

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions **Publication Guidance** Conclusion Citations 41 of 42

## 5.3 Minimum Reporting Size

### Minimum Reporting Size

Recommendations on a threshold minimum for public reporting of data

The United States Department of Education's Disclosure Review Board recommends a threshold rule that specifies the minimum reporting size for breakout categories in public reporting.

**For NBDC data, a threshold minimum of 10 is required in public reporting of data, including scientific publications and presentations.**



Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions **Publication Guidance** Conclusion Citations 41 of 42

Notes:

## 5.4 Privacy Protection Methods (1/5)


### Privacy Protection Methods (1/5)

Recommended privacy protection methods


The United States Department of Education's Disclosure Review Board also recommends the following privacy protection methods:

- Table cell suppression
- Data perturbation

These terms will be defined on the next slides.



[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) **[Publication Guidance](#)** [Conclusion](#) [Citations](#) 

Notes:


## 5.5 Privacy Protection Methods (2/5)

### Privacy Protection Methods (2/5)

#### Table cell suppression

There are two types of cell suppression:

- *Primary suppression* refers to the process of withholding data values in public reporting data that do not meet the threshold rule. To protect personally identifiable information, data categories that fall below the threshold are not displayed.
- *Complementary suppression* refers to excluding data that can be used to recover data that has undergone primary suppression (usually through basic subtraction).



Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions **Publication Guidance** Conclusion Citations 52 of 52

Notes:

## 5.6 Privacy Protection Methods (3/5)

### Privacy Protection Methods (3/5)

#### Data perturbation

The IES report describes data perturbation as the *intentional introduction of an element of uncertainty into the data*:

- Ranges – replacing specific data values with ranges (e.g., 5-9%), with a larger recorded range required for smaller subgroups
- Top and bottom coding – substituting “greater than 95%” for all percentage values that are above 95 percent and “less than 5%” for all values that are below 5 percent
- Rounding – altering a number to another approximately similar value (e.g., values of 1, 2, and 3 are reported as 2)

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions **Publication Guidance** Conclusion Citations 52 of 52

Notes:

### 5.7 Privacy Protection Methods (4/5)

#### Privacy Protection Methods (4/5)

How data perturbation and cell suppression can mitigate risk of participant identification

Non-complying			
	n	Mean	SD
Female	9	5.1	0.29
Male	14	5.3	0.3
Total	23		

Here's an illustration of how data perturbation and cell suppression can be used to mitigate risk of participant identification.

Data perturbation			
	n	Mean	SD
Female	≤10	5.1	0.29
Male	14	5.3	0.3
Total	≤24		

Note that the number of females (i.e., 9) is suppressed through primary suppression and the number of males (i.e., 14) is suppressed through complementary suppression.

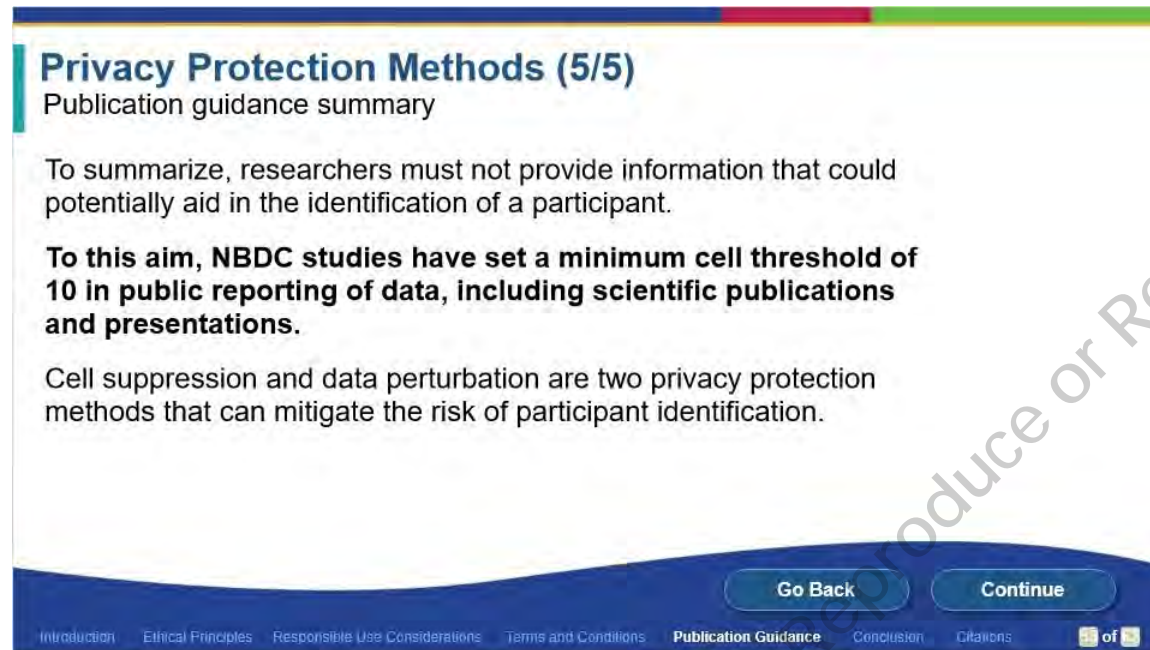
Primary and complementary suppression			
	n	Mean	SD
Female	*	5.1	0.29
Male	*	5.3	0.3
Total	23		

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions **Publication Guidance** Conclusion Citations 4 of 5

Notes:

## 5.8 Privacy Protection Methods (5/5)



**Privacy Protection Methods (5/5)**  
Publication guidance summary

To summarize, researchers must not provide information that could potentially aid in the identification of a participant.

**To this aim, NBDC studies have set a minimum cell threshold of 10 in public reporting of data, including scientific publications and presentations.**

Cell suppression and data perturbation are two privacy protection methods that can mitigate the risk of participant identification.

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions **Publication Guidance** Conclusion Citations 5 of 5

Notes:

## 6. Conclusion

### 6.1 Conclusion

# Conclusion

Thank you for completing the **Responsible Data and Biospecimen Use Training Module**.

The material presented in this training highlights the necessity of inclusive, fair, and just science. This training provides a brief overview of both historical and contemporary science but does not offer a comprehensive review of scientific practices and research contexts. Nor does it offer a finite checklist of recommended practices for doing responsible science. We encourage you to continue learning, reflecting, and asking questions as you develop your research projects, consider analytic approaches, and interpret your findings.

Please visit the [NBDC Data Hub](#) for information about ABCD and HBCD data resources.

These resources will be regularly updated.

If you have questions about the NBDC studies, please email [nbdc@mail.nih.gov](mailto:nbdc@mail.nih.gov).

[Go Back](#) [Continue](#)

56 of 62

Notes:

## 7. Citations and Additional Resources

### 7.1 Citations (1/5)

**Citations (1/5)**

1. [Ensuring the Best Use of Data: The Adolescent Brain Cognitive Development Study](https://pubmed.ncbi.nlm.nih.gov/31305867/)  
(<https://pubmed.ncbi.nlm.nih.gov/31305867/>)
2. [Advancing high quality longitudinal data collection: Implications for the HEALTHY Brain and Child Development \(HBCD\) Study design and recruitment](https://www.sciencedirect.com/science/article/pii/S1878929324000938)  
(<https://www.sciencedirect.com/science/article/pii/S1878929324000938>)
3. [Limits to the generalizability of resting-state functional magnetic resonance imaging studies of youth: An examination of ABCD Study® baseline data](https://pubmed.ncbi.nlm.nih.gov/35552993/)  
(<https://pubmed.ncbi.nlm.nih.gov/35552993/>)
4. [Why weight? Analytic approaches for large-scale population neuroscience data](https://pubmed.ncbi.nlm.nih.gov/36630774/)  
(<https://pubmed.ncbi.nlm.nih.gov/36630774/>)
5. [A Guide for Population-based Analysis of the Adolescent Brain Cognitive Development \(ABCD\) Study Baseline Data](https://www.biorxiv.org/content/10.1101/2020.02.10.942011v1)  
(<https://www.biorxiv.org/content/10.1101/2020.02.10.942011v1>)

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 57 of 60

Notes:

## 7.2 Citations (2/5)

### Citations (2/5)

- [The Belmont Report](https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf)  
(https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c\_FINAL.pdf)
- [The Tuskegee Timeline](https://www.cdc.gov/tuskegee/timeline.htm)  
(https://www.cdc.gov/tuskegee/timeline.htm)
- [The Legacy of Henrietta Lacks](https://www.hopkinsmedicine.org/henrietalacks/upholding-the-highest-bioethical-standards.html)  
(https://www.hopkinsmedicine.org/henrietalacks/upholding-the-highest-bioethical-standards.html)
- [Garrison 2012](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5310710/)  
(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5310710/)
- [Hart and Sobraske 2003](https://search.lib.asu.edu/discovery/fulldisplay?vid=01ASU_INST:01ASU&search_scope=MyInst_and_CI&tab=Everything&docid=alma991047650219703841&lang=en&context=L&isFrbr=true)  
(https://search.lib.asu.edu/discovery/fulldisplay?vid=01ASU\_INST:01ASU&search\_scope=MyInst\_and\_CI&tab=Everything&docid=alma991047650219703841&lang=en&context=L&isFrbr=true)
- [Wash Univ vs. Catalona](https://caselaw.findlaw.com/court/us-8th-circuit/1300306.html)  
(https://caselaw.findlaw.com/court/us-8th-circuit/1300306.html)

[Go Back](#) [Continue](#)

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 2 of 5

Notes:

## 7.3 Citations (3/5)

### Citations (3/5)

- [Words Matter - Terms to Use and Avoid When Talking About Addiction](https://nida.nih.gov/nidamed-medical-health-professionals/health-professions-education/words-matter-terms-to-use-avoid-when-talking-about-addiction)  
(https://nida.nih.gov/nidamed-medical-health-professionals/health-professions-education/words-matter-terms-to-use-avoid-when-talking-about-addiction)
- [Language Matters When Discussing Substance Use](https://www.thenationalcouncil.org/wp-content/uploads/2021/11/Language-Matters-When-Discussing-Substance-Use-1.pdf)  
(https://www.thenationalcouncil.org/wp-content/uploads/2021/11/Language-Matters-When-Discussing-Substance-Use-1.pdf)
- [Validity of Self-Reported Cannabis Use Among Pregnant Females in Northern California](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7931632/pdf/nihms-1674033.pdf)  
(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7931632/pdf/nihms-1674033.pdf)
- [Patterns of Prenatal Alcohol Use That Predict Infant Growth and Development](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6361345/)  
(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6361345/)
- [Polysubstance Use in Pregnancy: Surveillance, Interventions, and Next Steps](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10558011/)  
(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10558011/)
- [Meaningful associations in the adolescent brain cognitive development study](https://pubmed.ncbi.nlm.nih.gov/34147629/)  
(https://pubmed.ncbi.nlm.nih.gov/34147629/)

[Go Back](#) [Continue](#)

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 3 of 5

Notes:

## 7.4 Citations (4/5)

### Citations (4/5)

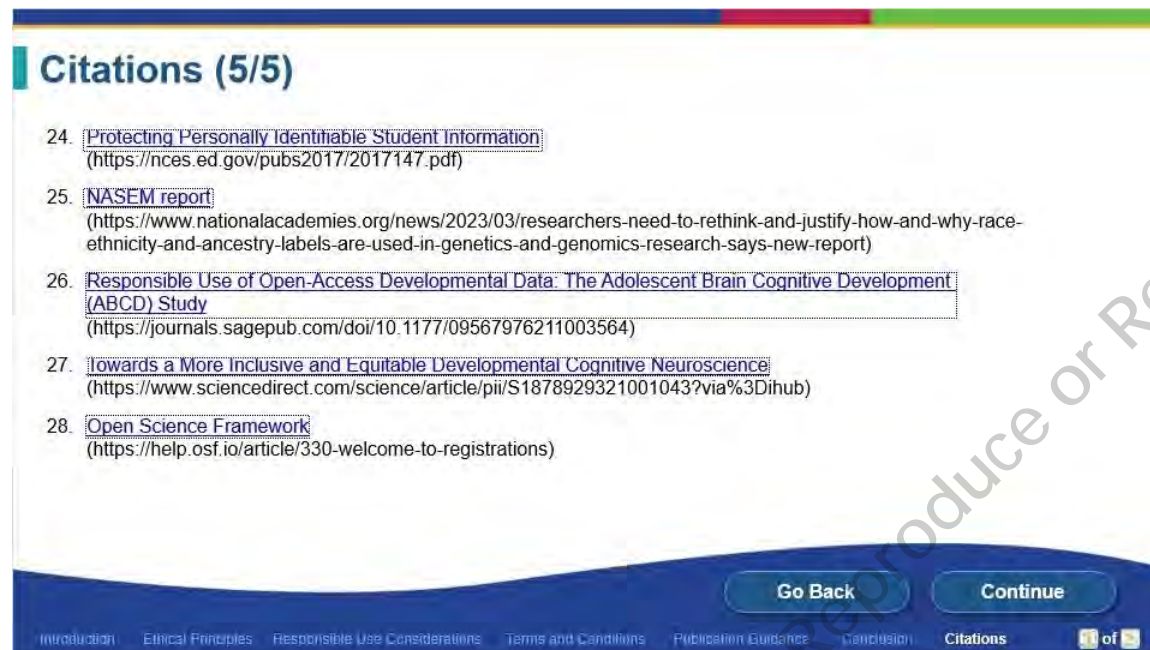
18. [Neuroethics beyond genetics](https://www.embopress.org/doi/epdf/10.1038/sj.embor.7401009_)  
([https://www.embopress.org/doi/epdf/10.1038/sj.embor.7401009\\_](https://www.embopress.org/doi/epdf/10.1038/sj.embor.7401009_))
19. [Best practices in data analysis and sharing in neuroimaging using MRI](https://www.nature.com/articles/nn.4500)  
(<https://www.nature.com/articles/nn.4500>)
20. [Brain charts for the human lifespan](https://www.nature.com/articles/s41586-022-04554-y)  
(<https://www.nature.com/articles/s41586-022-04554-y>)
21. [Developmental trajectories during adolescence in males and females: A cross-species understanding of underlying brain changes](https://www.sciencedirect.com/science/article/abs/pii/S0149763411000790)  
(<https://www.sciencedirect.com/science/article/abs/pii/S0149763411000790>)
22. [Limits to the generalizability of resting-state functional magnetic resonance imaging studies of youth: An examination of ABCD Study® baseline data](https://pubmed.ncbi.nlm.nih.gov/35552993/)  
(<https://pubmed.ncbi.nlm.nih.gov/35552993/>)
23. [Effects of different intracranial volume correction methods on univariate sex differences in grey matter volume and multivariate sex prediction](https://www.nature.com/articles/s41598-020-69361-9)  
(<https://www.nature.com/articles/s41598-020-69361-9>)

[Go Back](#) [Continue](#)

[Introduction](#) [Ethical Principles](#) [Responsible Use Considerations](#) [Terms and Conditions](#) [Publication Guidance](#) [Conclusion](#) [Citations](#) 4 of 4

Notes:

## 7.5 Citations (5/5)



### Citations (5/5)

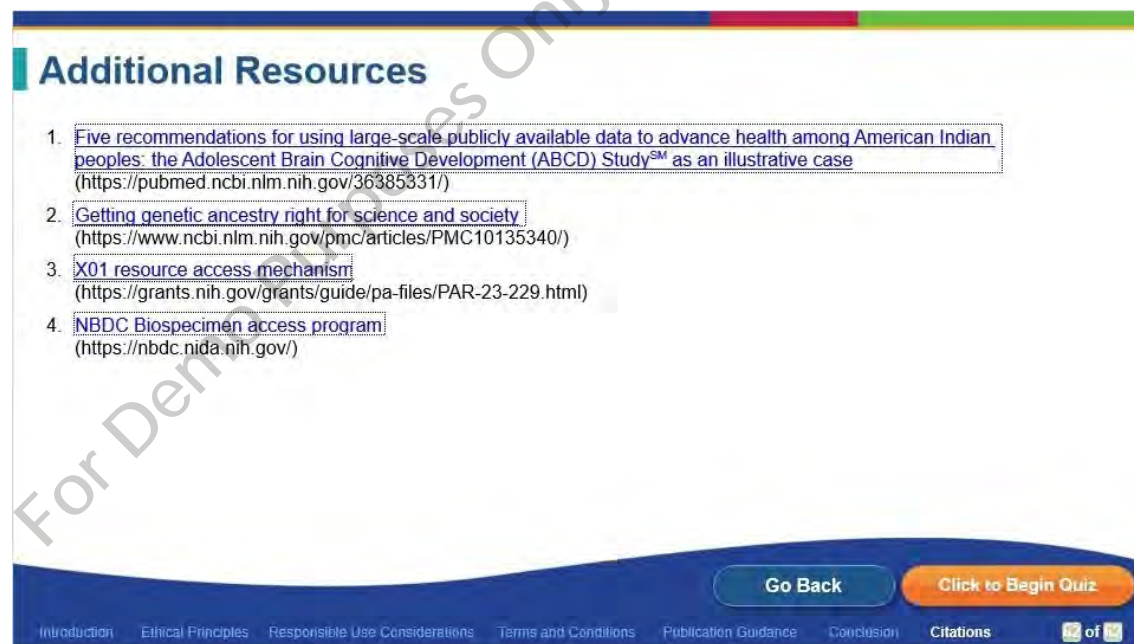
24. [Protecting Personally Identifiable Student Information](https://nces.ed.gov/pubs2017/2017147.pdf)  
(<https://nces.ed.gov/pubs2017/2017147.pdf>)
25. [NASEM report](https://www.nationalacademies.org/news/2023/03/researchers-need-to-rethink-and-justify-how-and-why-race-ethnicity-and-ancestry-labels-are-used-in-genetics-and-genomics-research-says-new-report)  
(<https://www.nationalacademies.org/news/2023/03/researchers-need-to-rethink-and-justify-how-and-why-race-ethnicity-and-ancestry-labels-are-used-in-genetics-and-genomics-research-says-new-report>)
26. [Responsible Use of Open-Access Developmental Data: The Adolescent Brain Cognitive Development \(ABCD\) Study](https://journals.sagepub.com/doi/10.1177/09567976211003564)  
(<https://journals.sagepub.com/doi/10.1177/09567976211003564>)
27. [Towards a More Inclusive and Equitable Developmental Cognitive Neuroscience](https://www.sciencedirect.com/science/article/pii/S1878929321001043?via%3Dihub)  
(<https://www.sciencedirect.com/science/article/pii/S1878929321001043?via%3Dihub>)
28. [Open Science Framework](https://help.osf.io/article/330-welcome-to-registrations)  
(<https://help.osf.io/article/330-welcome-to-registrations>)

Go Back Continue

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 11 of 12

Notes:

## 7.6 Additional Resources



### Additional Resources

1. [Five recommendations for using large-scale publicly available data to advance health among American Indian peoples: the Adolescent Brain Cognitive Development \(ABCD\) Study<sup>SM</sup> as an illustrative case](https://pubmed.ncbi.nlm.nih.gov/36385331/)  
(<https://pubmed.ncbi.nlm.nih.gov/36385331/>)
2. [Getting genetic ancestry right for science and society](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10135340/)  
(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10135340/>)
3. [X01 resource access mechanism](https://grants.nih.gov/grants/guide/pa-files/PAR-23-229.html)  
(<https://grants.nih.gov/grants/guide/pa-files/PAR-23-229.html>)
4. [NBDC Biospecimen access program](https://nbdc.nida.nih.gov/)  
(<https://nbdc.nida.nih.gov/>)

Go Back Click to Begin Quiz

Introduction Ethical Principles Responsible Use Considerations Terms and Conditions Publication Guidance Conclusion Citations 12 of 12

**Notes:**

For Demo Purposes Only: Do not Reproduce or Reuse