



Society for Research in Child Development
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The Honorable Jay Bhattacharya
Director
National Institutes of Health
U.S. Department of Health and Human Services
9000 Rockville Pike
Bethesda, MD 20982

April 23, 2026

RE: Adolescent Brain Cognitive Development (ABCD) Study's Children's Genetic Data

Dear Dr. Bhattacharya,

The Society for Research in Child Development ([SRCD](http://www.srkd.org)), along with the undersigned 169 members of the scientific community, writes to express our concerns regarding [recent reporting](#) in *The New York Times* (*NYT*) about the misuse of genetic and developmental data from the National Institutes of Health's Adolescent Brain Cognitive Development ([ABCD](#)) Study. As one of the most ambitious longitudinal studies on child development ever undertaken, the ABCD Study represents a landmark federal investment in understanding the cognitive, behavioral, neurological, and social development of children in the United States.

SRCD is a nonpartisan, multidisciplinary professional membership association representing developmental scientists from all 50 states, territories and the District of Columbia. Our members' work seeks to understand the factors that shape children's cognitive, behavioral, and social development, with substantial expertise in ethical research, anti-racist practices, and the interpretation and communication of research involving race, genetics and cultural contexts. SRCD has also developed professional ethical standards to guide responsible developmental science.

Recent [reporting](#) regarding the use of genetic data from the ABCD Study has raised serious concerns within the developmental science community and underscores the importance of addressing this issue with transparency and care for research participants.

SRCD respectfully requests NIH leadership to take immediate corrective action. The following sections outline the scientific and ethical principles that guide developmental research in our professional society, and explain why stronger safeguards, transparency, and accountability are necessary in this case. Specifically, we urge NIH to:

- Strengthen oversight of data access;
- Enhance participant notification protocols when misuse occurs; and

- Inform the public on the steps taken to address this incident and ensure accountability.

Ethical and Anti-Racist Principles in Scientific Research

The [report](#) states that individuals accessed and misused the genetic information of Asian, Black and Latinx children to advance racially discriminatory and scientifically unfounded claims. These claims contradict decades of established scientific consensus rejecting biological hierarchies of race, and raise serious questions regarding the stewardship and ethical use of data.¹ In this context, we request NIH and the broader scientific community uphold rigorous ethical standards that incorporate anti-racist principles in the conduct, interpretation, and communication of developmental science. At SRCD, we endeavor to lead the field in both ethics and anti-racism protocols and standards in developmental research.

SRCD's [Ethical Principles and Standards for Developmental Scientists](#) affirm that the conduct, interpretation, and communication of developmental science must be grounded in rigorous ethical standards, scientific integrity, and respect for the dignity and rights of research participants.² These principles emphasize the responsibility of researchers and institutions to safeguard participant privacy, prevent misuse of research findings, and ensure that developmental science is communicated in ways that do not expose individuals or communities to harm, and include:

- **Protecting the rights, dignity, and interests of research participants**, including safeguarding privacy and confidentiality and ensuring that research practices and data use do not expose individuals or communities to harm, exploitation, or misuse.
- **Preventing the misuse of research to perpetuate discrimination or injustice**, recognizing the responsibility of developmental science to ensure that scientific findings are not misrepresented or used in ways that reinforce harmful or scientifically unsupported claims about individuals or groups.
- **Upholding scientific integrity and accountability in the use and communication of research data**, including ensuring that data are analyzed, interpreted, and disseminated in accordance with established scientific standards, ethical norms, and institutional responsibilities.

¹ Fuentes, A., Ackermann, R. R., Athreya, S., Bolnick, D., Lasisi, T., Lee, S.-H., McLean, S.-A., & Nelson, R. (2019). *AAPA statement on race and racism*. *American Journal of Physical Anthropology*, 169(3), 400–402. <https://doi.org/10.1002/ajpa.23882>

² Society for Research in Child Development. (n.d.). *Ethical principles and standards for developmental scientists*. <https://www.srcd.org/about-us/ethical-principles-and-standards-developmental-scientists>

In addition, SRCD's [Anti-Racism Task Force](#) further affirms that ethical science requires deliberate attention to how research involving race, ethnicity, and human development is designed, interpreted, and communicated.³ SRCD has implemented these measures within its own scientific and publication practices to promote responsible research that serves our communities well by:

- **Requiring authors to situate their findings within appropriate sociocultural and developmental contexts**, including clearly describing the populations represented in their research and considering the social, environmental, and structural conditions that shape developmental outcomes.
- **Strengthening editorial leadership and peer review processes to promote fair, rigorous, and accountable evaluation of research**, including efforts to diversify editorial leadership and reviewer pools to ensure that research involving diverse populations is evaluated with appropriate scientific and contextual expertise.
- **Establishing institutional accountability for the responsible interpretation and dissemination of research findings**, including policies and practices designed to prevent misrepresentation or misuse of developmental data to ensure that scientific publications uphold established ethical and scientific standards.
- **Promoting transparency, accountability, and responsible stewardship of sensitive research data**, including recognizing institutional responsibility to ensure that data access, interpretation, and dissemination practices protect research participants and uphold scientific integrity.

We uphold these principles not as aspirational goals, but as fundamental and enforceable standards of the research enterprise and encourage the same commitment from NIH.

Strengthening Data Governance and Accountability in Federally Funded Research

This incident highlights the importance of strong governance systems for large-scale research initiatives that rely on sensitive developmental and genetic data. The research enterprise fundamentally relies on the trust of the public.⁴ When concerns arise about how sensitive research data is used or interpreted, that trust, and the willingness to participate

³ Society for Research in Child Development. (2021). *SRCD Anti-Racism Task Force full final report*. <https://www.srcd.org/srcd-anti-racism-task-force/srcd-anti-racism-task-force-full-final-report>

⁴ National Academies of Sciences, Engineering, and Medicine. (2023). *Using population descriptors in genetics and genomics research: A new framework for an evolving field*. The National Academies Press. <https://doi.org/10.17226/26902>

in research, can be undermined, particularly among communities that have historically experienced harm or exploitation in scientific research.⁵

This is why it's imperative for accountability to be clear, commensurate with the severity of misconduct, and visible to the public. The absence of evident consequences risks signaling institutional tolerance for practices that undermine public confidence, and normalize harmful rhetoric directed at already vulnerable communities.

Furthermore, this incident highlights the need to modernize data governance systems. Protection of participant data must extend beyond initial consent and access approvals. Institutions should implement regular audits of data access, strengthen oversight of secondary use, and conduct proactive risk assessment to potential identity misuse, including by bad-faith actors. Clear protocols must also ensure timely notification to participants when misuse occurs.

Advancements in artificial intelligence further amplify the risks associated with genetic data.⁶ De-identification and safeguard tools must evolve according to emerging technological capabilities to ensure updated protocols that protect confidentiality.⁷ These protocol revisions are urgent, and we urge NIH to take immediate action to strengthen and modernize relevant safeguards.

Request for Clarification and Engagement

Given the importance of maintaining public confidence in federally funded research, SRCDC respectfully encourages NIH leadership to clarify the circumstances described in recent reporting, and the steps being taken to address this matter.

We encourage NIH to:

- **Strengthen oversight of data access**, including reviewing existing controls governing the use of sensitive developmental and genetic datasets.
- **Enhance protocols for notifying research participants when misuse occurs**, ensuring that families are informed in a timely and transparent manner when concerns arise regarding the use of their data.

⁵ Scharff, D. P., Mathews, K. J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). *More than Tuskegee: Understanding mistrust about research participation*. *Journal of Health Care for the Poor and Underserved*, 21(3), 879–897. <https://doi.org/10.1353/hpu.2010.0233>

⁶ Bonomi, L., Huang, Y., & Ohno-Machado, L. (2020). *Privacy challenges and research opportunities for genomic data sharing*. *Nature Genetics*, 52(7), 646–654. <https://doi.org/10.1038/s41588-020-0651-0>

⁷ El Emam, K., Arbuckle, L., & Skeff, K. (2015). *A critical appraisal of the evidence on the re-identifiability of genomic data*. *Journal of the American Medical Informatics Association*, 22(2), 243–248. <https://doi.org/10.1093/jamia/ocu023>

- **Inform the public of the steps being taken to address this incident and ensure accountability**, including measures implemented to strengthen safeguards for developmental and genetic data moving forward.

SRCD also welcomes the opportunity to engage directly with NIH leadership on these issues. Our members have substantial expertise in the ethical conduct of research involving children, and how to properly interpret findings and communicate results with families and racially marginalized communities. We welcome the opportunity to support NIH's efforts to strengthen protections for research participants and promote responsible use of developmental and genetic data across the research enterprise.

Maintaining public trust in federally funded research requires transparency and accountability. Forcefully and transparently addressing incidents such as the one described in recent reporting is essential to reinforcing that trust and ensuring continued confidence by all parties and the public in large-scale developmental studies.

Thank you for your attention to this important matter. At SRCD, we welcome NIH's response and would appreciate any information you are able to share regarding the steps taken to address this issue.

Please direct any correspondence to Kent Mitchell, SRCD Director of Policy at kmitchell@srcd.org.

Sincerely,

The Society for Research in Child Development (SRCD)

Cc:

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