



January 13, 2025

Submitted Electronically: <https://www.regulations.gov>

National Telecommunications and Information Administration (NTIA)
Department of Commerce

RE: Request for Public Comments Concerning Ethical Guidelines for Research Using Pervasive Data (Dept. of Commerce Docket No. 241204-0309; RIN 0660-XC064; Regulations.gov Docket No. NTIA-2024-0004)

To Whom it May Concern:

We write to offer comments in response to the request for public comments concerning Ethical Guidelines for Research Using Pervasive Data (“Request”) published in the Federal Register on December 11, 2024. [[89 F.R. 99844](#)].

COGR is the national authority on federal policies and regulations affecting U.S. research institutions. We provide a unified voice for over 220 research universities and affiliated academic medical centers and research institutes. Our work strengthens the research partnership between the federal government and research institutions and furthers the frontiers of science, technology, and knowledge. We advocate for effective and efficient research policies and regulations that maximize and safeguard research investments and minimize administrative and cost burdens.

COGR and its member institutions fully support the need to ensure that research is conducted in an ethical manner that protects the privacy and confidentiality of individuals whose information is collected and analyzed. We also appreciate the growing importance of ensuring investigators’ ability to conduct research using “pervasive data,” which is defined by the Request as “data about people – user-contributed, observed, derived, or inferred – collected through online services regardless of the extent to which the data is publicly available, is aggregated, or could lead to the identification of an individual.”

Our comments address Question 2 of the Request: *What are the potential drawbacks of developing national-level ethical guidelines for researchers, collecting analyzing and sharing pervasive data?*

As the Request states, not all research that utilizes pervasive data will be considered research involving human subjects that falls within the scope of the Common Rule and Belmont Report. Further, depending on the type of data, who collects it, associated identifiers, and the parties conducting and funding the research, various federal and state privacy and confidentiality laws, regulations, and policies may apply.¹ Finally, as the Request notes,

¹ See, e.g., HIPAA Privacy Rule, 45 C.F.R. Part 160 and Part 164, Subparts A & E; Confidentiality of Substance Use Disorder Patient Records, 42 C.F.R. Part 2; [Certificates of Confidentiality for NIH Funded Research](#); Family Education Rights and Privacy Act, 34 C.F.R. Part 99; Int’l Assoc. of Privacy Professionals (IAPP), [U.S. State Privacy Legislation Tracker 2025, Comprehensive Consumer Privacy Bills](#) (including enacted laws).

multiple institutions, public and private, have drafted various types of ethical guidelines to govern diverse types of research using pervasive data.²

Accordingly, we urge NTIA to proceed with extreme caution in considering whether to introduce yet another set of guidelines into an already overwhelmingly large and complex collection of existing laws, regulations, standards, policies, and guidance. Indeed, one of the major challenges researchers face is how to navigate the often-confusing processes of determining which of the many existing federal, state, institutional, and professional requirements or guidelines apply to the type of research they are conducting.

We do not believe NTIA is the most appropriate agency to lead efforts to develop ethical guidelines for the research use of pervasive data. Rather, we believe the Department of Health and Human Services (HHS) is best equipped to lead such an effort. HHS funds the vast amount of research involving data from humans³ and has explicit statutory authority to establish a program that provides guidance regarding ethical issues associated with that research.⁴ The Department of Commerce ranked fifth out of the top ten agencies in federal research and development funding from FY2022 – FY2024, while HHS and the Department of Defense far surpassed all of the other agencies in terms of budget authority.⁵

If NTIA decides to develop non-binding ethical guidelines for research using pervasive data, we strongly urge NTIA to embark on this project as part of a larger collaboration with other federal research funding agencies. Such a collaborative effort would avoid the all-too-common scenario of multiple federal agencies issuing similar, but not identical, guidelines on a topic of mutual interest and concern. Indeed, the development of a single set of guidelines endorsed by all major research funding agencies would have a much greater impact on promoting consistent ethical practices among researchers using pervasive data, than a single agency issuing its own set of guidelines.

We appreciate the opportunity to comment on the Request. Should you have any questions regarding these comments, please contact me or Kristin West, COGR's Director of Research, Ethics and Compliance at kwest@cogr.edu.

Sincerely,



Matt Owens
President

² 89 F.R. at 99846.

³ Congressional Research Service (CRS), [Federal Research and Development \(R&D\) Funding: FY 2024](#) (May 19, 2023) ("CRS Report") at p. 17-18.

⁴ See, 42 U.S.C. §289.

⁵ CRS Report, *supra* n. 3, Table 1 at p. 4.