



FASEB

Federation of American Societies
for Experimental Biology

Representing Over 115,000 Researchers

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March 31, 2014

Nicole Wong, JD
Office of Science and Technology Policy
Eisenhower Executive Office Building
1650 Pennsylvania Ave. NW
Washington, DC 20502

RE: Request For Information: Government “Big Data”

Comments submitted electronically to: bigdata@ostp.gov

Dear Ms. Wong:

The Federation of American Societies for Experimental Biology (FASEB) is composed of 26 scientific societies, collectively representing more than 115,000 researchers. FASEB recognizes the increasingly important role “big data” plays in research and throughout society. We thank the Office of Science and Technology Policy (OSTP) for this opportunity to provide comments on government “big data” and resulting privacy issues. Our comments are drawn from previous FASEB statements that address different aspects of government “big data” as related to biomedical and life science research. We have appended the relevant statements to this response and call your attention to several points that are most pertinent to the questions listed in the OSTP request for information (RFI).

Responses to questions 1-3 and 5 from the OSTP RFI:

- (1) Current U.S. policy frameworks and privacy proposals are insufficient to ensure the privacy of human research subjects in perpetuity. In comments on the proposed National Institutes of Health (NIH) Genomic Data Sharing Policy (see attached), FASEB stated that “de-identification cannot be guaranteed for certain types of data, including whole genomic sequences.” FASEB, therefore, recommended the consideration of alternative models to protect human research subjects, such as shifting from a privacy-protection paradigm to “one that provides research subjects with substantive legal protections against the misuse of or inappropriate access to their data.”
- (2) In several statements, FASEB has noted the potential value of “big data” analysis and data sharing. These possible benefits include improved health, quality of life, and clinical care, as well as the development of new and transformative technologies.
- (3) There is a critical need for more tools and systems to promote high quality metadata collection. The development of these is essential to the creation of datasets and their ultimate utility (see attached comments on the proposed NIH Data Catalog).

However, the possibility of re-identification of individuals increases as more data from both research and non-research sources become available, scientific knowledge increases, and analytical tools improve.

- (5) FASEB is currently developing comments to submit to the Institute of Medicine (IOM) request for public feedback on the responsible sharing of data from clinical trials that address variation across international regulations. We encourage OSTP to review the ongoing IOM study and discussion framework document. We are also willing to share our comments to IOM with OSTP once they are available.

FASEB appreciates your consideration of our comments and looks forward to working with OSTP on these issues. Please let us know if we can be of further assistance.

Sincerely,

A handwritten signature in black ink, appearing to read "Margaret K. Offermann". The signature is written in a cursive style with a horizontal line extending from the end.

Margaret K. Offermann, MD, PhD
FASEB President

Attachments

[FASEB Comments on the draft NIH Policy for Genomic Data Sharing](#)

[FASEB's Response to the Request for Information on the Development of an NIH Data Catalog](#)