

ACTION NEEDED: Please add your voice and expertise to government policy implementation

National Cancer Institute sent this bulletin at 11/19/2024 04:08 PM EST



Dear Colleagues,

Please <u>consider adding your critical scientific and cancer clinical care insights</u> on an important proposed federal rule that could affect how data, particularly omics data, are shared internationally. All feedback needed by Friday November 29th; government needs specific details and references for all appropriate context and considerations, to ensure completeness.

A few weeks ago, the United States Justice Department issued a Notice of Proposed Rulemaking (NPRM) in response to President Biden's Executive Order 14117 (issued Feb. 28, 2024: "Preventing Access to Americans' Bulk Sensitive Personal Data and United States Government-Related Data by Countries of Concern"). The order addresses potential security threats posed by any unregulated access to or exploitation of certain kinds of sensitive personal data from American citizens.

This proposed rule addresses the concerns outlined in the executive order by establishing rules for certain data transactions that could pose an unacceptable level of risk for US sensitive data (particularly omics or other potentially identifiable health information) when provided in bulk to countries that may pose a national security threat.

The Justice Department seeks specific feedback (e.g. general comments or concerns, real world examples, scientific risk and assessment considerations on the proposed rule for omics) from the broad community including **genomics experts**, **government funded scientists**, **health/omics data industry**, **patient advocates**, **organizations and entities** potentially affected by the proposed rule, and others with interest in the rule or expertise on data security and cybersecurity. The public may submit written comments on the NPRM at www.regulations.gov.

Critical Resources:

- Link for comments
- Notice of Proposed Rulemaking (NPRM)
- DOJ Fact Sheet
- DOJ Press Release
- Presidential Executive Order

Please email the Office of Data Sharing with any specific questions.

We'd love to hear from you! Contact the ODS team at: nciofficeofdatasharing@mail.nih.gov

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