

October 11, 2019

The Honorable Rosa DeLauro  
Chairwoman  
Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
U.S. House Committee on Appropriations

The Honorable Roy Blunt  
Chairman  
Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
U.S. Senate Committee on Appropriations

The Honorable Tom Cole  
Ranking Member  
Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
U.S. House Committee on Appropriations

The Honorable Parry Murray  
Ranking Member  
Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
U.S. Senate Committee on Appropriations

**RE: Maintain Unique Health Identifier Funding Prohibition in FY 2020 Labor-HHS Appropriations Bill**

Dear Chairwoman DeLauro, Chairman Blunt and Ranking Members Cole and Murray:

As you work to finalize the FY 2020 appropriations bill for the Departments of Labor, Health and Human Services (HHS), Education, and Related Agencies (“FY 2020 Labor-HHS appropriations bill”), we write to strongly urge you to maintain an important provision protecting Americans’ medical privacy, which was included in the Senate Committee on Appropriations’ subcommittee chairman’s recommendation for the FY 2020 Labor-HHS appropriations bill.<sup>1</sup>

Section 262 of the Health Insurance Portability and Accountability Act of 1996 requires the Secretary of HHS to adopt standards providing for a standard unique health identifier for each individual, employer, health plan, and health care provider for use in the health care system.<sup>2</sup> However, since FY 1999, Congress has included language in each Labor-HHS appropriations bill blocking the department from spending funds to promulgate regulations for the adoption of a unique health identifier for an individual unless Congress approves the standards. Section 510 of the Senate Committee on Appropriations’ subcommittee chairman’s recommendation for the FY 2020 Labor-HHS appropriations bill wisely maintains this prohibition. However, the House-passed FY 2020 Labor-HHS appropriations bill incorporated an amendment striking this prohibition.<sup>3</sup>

Given the profound sensitivity of medical information and the potential threat to individuals’ privacy rights, we strongly urge you to maintain the language in Section 510 of the Senate

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<sup>1</sup> STAFF OF S. COMM. ON APPROPRIATIONS, 116<sup>TH</sup> CONG., MAKING APPROPRIATIONS FOR THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES FOR THE FISCAL YEAR ENDING SEPTEMBER 30, 2020, AND FOR OTHER PURPOSES. 164 (Comm. Print) available at <https://www.appropriations.senate.gov/imo/media/doc/FY2020%20Labor-HHS%20Appropriations%20Act.%20Bill%20Text.pdf>.

<sup>2</sup> Section 262 of the Health Insurance Portability and Accountability Act of 1996 amended the Social Security Act of 1935 to add, among other things, Section 1173(b). See 42 U.S. Code § 1320d–2(b).

<sup>3</sup> "H.R. 2740 Labor, Health and Human Services, Education, Defense, State, Foreign Operations, and Energy and Water Development Appropriations Act, 2020: Roll Vote No. 270." Congressional Record 165:98 (June 12, 2019) p. H4588.

Committee on Appropriations' subcommittee chairman's recommendation for the FY 2020 Labor-HHS appropriations bill:

**If Congress removes this prohibition, it could be interpreted as allowing the development of a national unique health identifier without legislative approval.** For more than 20 years, Congress has prohibited regulations creating a unique health identifier for an individual unless Congress approves the standards.<sup>4</sup> By striking this provision in its entirety, Congress could jeopardize its role in approving unique health identifier standards, potentially paving the way for a de facto national medical I.D. system absent Congressional approval. The dangers of having a system like this compromised or inappropriately used or accessed to track individuals are profound. For this reason, our organizations have historically opposed national I.D. systems, like a national unique health identifier, because of the threat they pose to privacy rights.

**Given the sensitivity of medical information, Congress should approve the standards surrounding the use of unique health identifiers.** Absent strong privacy protections, use of unique health identifiers could empower HHS and potentially other federal agencies (including law enforcement) to gain unprecedented access to sensitive medical information. For this reason, it is critical that any use of unique health identifiers be subject to strict privacy and security protections, which are approved by Congress and subject to public debate.

**Historically, we have seen examples of inadequate health privacy regulations, underscoring the importance of requiring Congressional approval of health privacy standards in this arena.** For example, in 1999 the CDC issued draft guidance recommending states institute case reporting of individuals who tested positive for HIV, supporting a name-based identification system.<sup>5</sup> Previously, HHS has issued proposed regulations that would give law enforcement officials unfettered access to patient medical records, without requiring patient consent.<sup>6</sup> Given this history, it is critical that any regulations permitting a unique health identifier be approved by Congress.

**Existing law does not prohibit HHS from studying or examining the uses of unique health identifiers to inform future legislation.** The House Appropriations Committee made this clear in the FY 2019 Labor-HHS Appropriations committee report, stating “Although the committee continues to carry a prohibition against HHS using funds to promulgate or adopt any final standard providing for the assignment of a unique health identifier for an individual until such activity is authorized, the Committee notes that this limitation does not prohibit HHS from examining the issues around patient matching.” The Committee encouraged HHS to “provide technical assistance to private-sector-led initiatives to develop a coordinated national strategy” for the purpose of promoting patient safety.<sup>7</sup>

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<sup>4</sup> H.R.4328 - Omnibus Consolidated and Emergency Supplemental Appropriations Act, 1999, Pub. L. 105–277, § 516, 112 Stat. 2681 (1998).

<sup>5</sup> Centers for Disease Control and Prevention, *Guidelines for National Human Immunodeficiency Virus Case Surveillance, Including Monitoring for Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome* (1999) available at <https://www.cdc.gov/mmwr/preview/mmwrhtml/rr4813a1.htm>.

<sup>6</sup> *A National ID Card: Big Government at its Worst or Technological Efficiency? Before the Subcomm. On Nat'l Economic Growth, Natural Resources and Regulatory Affairs of the H. Comm. On Government Reform and Oversight*, 105<sup>th</sup> Cong. 32 (1998) (statement of Solange E. Bitol, Legislative Counsel, American Civil Liberties Union).

<sup>7</sup> H.R. Rep No. 115-862, at 121 (2018).

By removing this funding prohibition, Congress could pave the way for a de facto national medical I.D. system and permit inadequate unique health identifier regulations. This system would not only threaten individuals' privacy rights but also raise significant concerns regarding the protection of sensitive medical information. For these reasons, we urge you to maintain the unique health identifier funding prohibition in the FY 2020 Labor-HHS appropriations bill. If you have any questions, please contact Neema Singh Guliani (ACLU) at [nguliani@aclu.org](mailto:nguliani@aclu.org) and Jason Pye (FreedomWorks) at [jpye@freedomworks.org](mailto:jpye@freedomworks.org).

Sincerely,

American Civil Liberties Union  
FreedomWorks

cc: Chairwoman Nita Lowey  
Chairman Richard Shelby  
Ranking Member Kay Granger  
Vice Chairman Patrick Leahy