

June 12, 2019

RE: Vote “NO” on Foster-Kelly Amendment #20 to Minibus Appropriations Bill (H.R. 2740)

The American Civil Liberties Union (ACLU) strongly urges you to vote “NO” on Amendment #20 offered by Representatives Foster (IL) and Kelly (PA) to H.R. 2740. This amendment would strike Section 510 of the Labor-HHS Appropriations bill, a provision blocking the Department of Health and Human Services (HHS) from spending funds to promulgate regulations for the adoption of a unique health identifier for an individual unless Congress approves the standards. This requirement has existed in the law for nearly two decades. **While we do not take a position on the overall legislation, the ACLU will score this vote.**



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Given the profound sensitivity of medical information and the potential threat to individuals’ privacy rights, this amendment raises significant civil liberties concerns. Specifically:

- **The amendment could be interpreted as allowing the development of a national unique health identifier without legislative approval.** Since FY 1999, Congress has prohibited regulations creating a unique health identifier unless Congress approves the standards.¹ By striking Section 510 in its entirety, the Foster-Kelly amendment would eliminate Congress’s 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, the ACLU has 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.

¹ H.R.4328 - Omnibus Consolidated and Emergency Supplemental Appropriations Act, 1999, Pub. L. 105-277, § 516, 112 Stat. 2681 (1998).

- **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.² Previously, HHS has issued proposed regulations that would give law enforcement officials unfettered access to patient medical records, without requiring patient consent.³ 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 bill, 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.⁴

By striking Section 510, the amendment could provide the foundations for a 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 vote “NO” on the Foster-Kelly amendment.

If you have any questions, please contact Neema Singh Guliani, Senior Legislative Counsel at nguliani@aclu.org.

Sincerely



Ronald Newman
National Political Director



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² 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>.

³ *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*, 105th Cong. 32 (1998) (statement of Solange E. Bitol, Legislative Counsel, American Civil Liberties Union).

⁴ H.R. Rep No. 115-862, at 121 (2018).