

Statement for the Record
American College of Physicians
Markup before the House Energy & Commerce Committee
June 27, 2024

The American College of Physicians (ACP) appreciates the opportunity to submit this statement for the House Energy & Commerce Committee's [markup](#) of the [Telehealth Modernization Act](#), H.R. 7623, and the [American Privacy Rights Act](#), H.R. 8818. We appreciate Chair Rodgers and Ranking Member Pallone for their commitment to bring bipartisan legislation forward that would enhance patients' access to care and strengthen data privacy protections. ACP strongly supports extending the telehealth flexibilities that are scheduled to expire at the end of this year. Further, we previously [endorsed](#) the American Data Privacy Protection Act (ADPPA), and are pleased to see that American Privacy Rights Act (APRA) includes many of the provisions we support in the ADPPA. We urge the Energy and Commerce Committee (committee) to support the following policy recommendations, outlined in this statement, to improve the health and privacy for Americans across the country.

ACP is the largest medical specialty organization and the second-largest physician membership society in the United States. ACP members include 161,000 internal medicine physicians, related subspecialists, and medical students. Internal medicine physicians are specialists who apply scientific knowledge, clinical expertise, and compassion to the preventive, diagnostic, and therapeutic care of adults across the spectrum from health to complex illness.

ACP Supports the Telehealth Modernization Act, H.R. 7623

The College supports the expanded role of telehealth as a method of health care delivery that can enhance the patient-physician relationship, improve health outcomes, increase access to care, and reduce medical costs. Telehealth can be an option for patients who lack access to in-person primary or specialty care due to various social drivers of health such as a lack of transportation or paid sick leave, or insufficient work schedule flexibility to seek in-person care during the day. In order to preserve patients' access to care, Congress must extend telehealth flexibilities beyond this year.

ACP [strongly supports](#) the Telehealth Modernization Act of 2024. H.R. 7623 would extend telehealth flexibilities that ACP supports through 2026. This includes the removal of geographic restrictions, expansion of originating sites required for telehealth visits, and audio-only telehealth access. Further, it would allow for Federally Qualified Health Centers (FQHCs) and Rural Health Clinics (RHCs) to continue providing telehealth services to American seniors. These centers and clinics play a critical role in increasing access to care for patients across the country. They provide comprehensive care, including primary and preventive care services, for millions of Americans in medically underserved communities.

Moreover, we appreciate the provisions in the bill to reform pharmacy benefit manager (PBM) practices that have contributed to the rising costs of prescription drugs. ACP supports improving transparency, accountability, and competition in PBM practices to reduce the price of prescription drugs for our patients. Prescription drug prices have [increased](#) by more than 10 percent per year for each of the top 20 brand-name drugs prescribed to seniors, and PBMs negotiate rebates from those higher prices. Increased transparency from PBMs and health plans is needed to provide greater understanding of drug prices, help patients make informed decisions, and support a more



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sustainable health care system. There needs to be greater transparency to reduce confusion about how PBMs work and how they make decisions regarding formularies. This legislation would provide much needed clarity on the amount of money PBMs take in and the actual savings that get passed on to patients.

ACP Urges Congress to Pass a Comprehensive Data Privacy Framework

APRA would establish the nation's first comprehensive federal consumer data privacy framework, which has been an ACP priority for many years. Since the enactment of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), we have seen significant advancements in health care and information technology, including the use of personal health information (PHI) shared within non-HIPAA-covered entities. ACP is greatly concerned that once information is disclosed to a health app or other third-party applications or entities, it loses its HIPAA privacy protections, and that data could be used against patients and/or health care professionals when searching for and/or furnishing health services.

The United States needs a comprehensive, national data privacy standard, rather than just relying on sector-specific federal privacy statutes that establish varying degrees of protection that can be insufficient. The most extensive privacy protections currently fall under HIPAA and address PHI that is collected or held by HIPAA-covered entities (clinicians, health plans, health care clearinghouses) and their business associates and exchanged within traditional health care settings and operations. Today, there are no laws that require non-HIPAA-covered entities such as mobile health applications (health apps), internet search engines, and large data brokers to notify app users when they collect, use, share, or sell app users' PHI.

There is a growing consensus among American consumers that mobile apps are collecting too much personal consumer data. In fact, a 2021 [study](#) by KPMG showed that 70 percent of companies increased their collection of personal consumer data despite 86 percent of consumers citing data privacy as a growing concern. Another [study](#) by the Pew Research Center indicated that half of American adults now say they have decided not to use a product or service due to worries over the use of their data. The United States needs to do better at protecting consumers' personal data, including PHI, and preventing companies from profiting from sharing the data with third parties for their own financial gain without consumers' consent and knowledge.

In ACP's health information privacy [2021 position paper](#), published in the *Annals of Internal Medicine*, ACP provides [six key principles](#) for health information privacy, protection, and use. These principles would improve privacy protections for PHI in the growing digital landscape. **ACP strongly supports the development and implementation of health information privacy and security protections that are comprehensive, transparent, understandable, adaptable, and enforceable. Further, any expanded federal data privacy framework should protect PHI from unauthorized, discriminatory, deceptive, or harmful uses. It is equally vital that privacy guardrails be expanded and extended to entities not currently governed by privacy laws and regulations.**

Recommendations to Improve APRA's Privacy Protections

While we understand that APRA's reach goes beyond health care data, which has enjoyed robust privacy protections under HIPAA, the policy reforms within APRA for non-HIPAA-covered entities



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that gather PHI align with ACP's privacy principles. The legislation would not only establish a national data privacy standard, but it would also expand data privacy protections to entities that are not currently subject to HIPAA privacy protections or regulations, both of which ACP strongly supports. Further, it would give consumers various rights to access, correct, and delete their data and opt-out of targeted advertisement and data transfers. It would also require, absent a specific exception, that entities obtain a consumer's express affirmative consent before transferring their "sensitive covered data" (which includes, among other things, health information, geolocation information, and private communications) to a third party. Given the increase in data breaches over the last several years, we appreciate that APRA contains provisions that would require companies to establish data security practices, assess systems' vulnerabilities, and avoid potential risks to consumer data.

While the College [supports](#) many of the privacy protections in APRA, it is important to note that we are deeply disappointed that the latest iteration of APRA no longer includes provisions that would prohibit companies from using algorithms to discriminate against consumers. We urge the committee to consider adding Section 113, entitled "Civil Rights and Algorithms," from the [previous iteration of APRA](#) back into the legislation. Further, we recommend that the committee includes provisions that would provide states with more flexibility to enact additional data privacy legislation, based on the needs of their residents, and allow for stronger confidentiality requirements for research data on human subjects.

Recommendations

As the committee considers APRA for markup, we offer the following recommendations that align with ACP's policy, to further strengthen the APRA:

- **Include Section 113 on Civil Rights and Algorithms from the previous iteration of APRA**

ACP strongly supports Section 113, which would prohibit companies from using consumers' personal data to discriminate or take adverse action against them. Further, it would give consumers the option to opt-out of allowing companies to use algorithms based on their personal data when they are making important life decisions such as those related to insurance, health care, housing, employment, and education. In ACP's recently published policy position paper on [Artificial Intelligence in the Provision of Health Care](#), the College underscores our support for policies that would prohibit the use of discriminatory algorithms in health care.

- **Allow States to Further Protect their Residents**

ACP supports a data privacy policy that would provide HIPAA protections for PHI moving outside of traditional health care environments or when collected and used by entities not covered under existing HIPAA rules. While we appreciate that APRA would provide a strong, comprehensive federal standard that states can adhere to, we support providing states with flexibility to further improve data privacy standards to fit their residents' needs. Because not all states have faced or will face the same threat of privacy violations or data breaches, they should not be constrained to a standard that may limit their ability to further protect



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their residents. **Thus, we urge you to consider ensuring that APRA will serve as a national standard for states to build upon based on each state's data privacy goals.**

- **Improve Transparency Practices for Research Data on Human Subjects**

While we appreciate the legislation's intent to ensure privacy protections for research data on human subjects, we urge continued caution in this area in the interest of our patients. **ACP policy states that each research subject or an authorized representative must be fully informed of the nature and risks of the research so that they may give informed consent to participate.** Some groups may be more vulnerable to coercion or undue influence (such as children, prisoners, individuals with impaired decision-making capacity, and economically or educationally disadvantaged persons, as included in the Common Rule (i.e., Part 46 of Title 45 Code of Federal Regulations)).

While the Common Rule and some state laws have provisions regarding privacy and confidentiality requirements for research, the HIPAA Privacy Rule requires subject authorization for the use or disclosure of protected health information for research. A privacy board can waive the authorization requirement, or information can be used in a "limited data set" with a data use agreement, or it can be deidentified under HIPAA, although the HIPAA deidentification requirements are stricter than those under the Common Rule. **We urge you to consider including a provision similar to the HIPAA Privacy Rule or Common Rule to improve confidentiality requirements for research data on human subjects.**

In conclusion, we thank you for the opportunity to offer a clinician perspective on these pressing issues. Should the committee seek input from the physician community, ACP has members who are willing to testify, as internal medicine represents 24 percent of the physician workforce in this country. We stand ready to serve as a resource to promote these policies as these bills are considered further by the House of Representatives. Should you have any questions, please contact Vy Oxman, Senior Associate of Legislative Affairs, at voxman@acponline.org.