2024-28

RESOLUTION

Subject: Protecting Medical Research and Improving Access to Care Amendment to HIPAA

Submitted by: William Richardson, MD, Julie Lee, MD, Frank Burns, MD, Ben Mackey, MD, Ben Proctor, MD, Ryan Smith, MD, and Jeremy Clark, MD

Referred to: Reference Committee

WHEREAS, the ACA and subsequent MACRA/MIPS (quality initiatives) created an enormous compliance burden on doctors, including EMR costs, IT support, charting time, registry connection/paperwork, and time away from patients. For example, the AMA states MIPS compliance costs $12,800 per provider, per year. Physicians spend 53 hours per year on compliance and pay for hundreds of administrative hours. As a result, achieving the incentive becomes more difficult each year. In fact, less than half of practices will see small bonuses from MIPS in 2024, and the penalties can reach 9% for non-compliance. It is much more difficult for small, rural practices to comply; and

WHEREAS, physicians are providing structured and unstructured data to the various specialty and medical device Registries that spawned to assist in MIPS compliance. Registries help physicians submit their MIPS quality data by running software in the EMR that uploads all patient information then curates a set for Medicare compliance. Not surprisingly, this data has become extremely valuable to the pharma industries for medical research, much more than the Medicare data set alone; and

WHEREAS, MIPS has now created multi-million-dollar Registries that enjoy "free" data, as HIPAA prevents physicians from sharing in the Fair Market Data Value. Registries enjoy the fact that MIPS penalties keep EMR data flowing. Most physicians do not realize that their Registry contracts allow this; and

WHEREAS, medical research for pharma, etc. has evolved leaps and bounds because of these Registries. However, medical research can be VASTLY improved by including imaging and other diagnostic data that is not captured by the existing Registries. Physicians currently have zero incentive to participate in anything more than what it takes to avoid MIPS penalties; and

WHEREAS, Medicare and Medicaid patients are desperate for physicians, and physicians are opting out or retiring at higher rates since COVID. Physician burnout is greater than 50%, and an entire medical school class is lost every year to suicide. 40% of physicians report that they will be doing “something else” in the next 2 years. Medicare reimbursement has dropped 26% (inflation adjusted) in the last 20 years. Inflation and labor costs are escalating; practice costs are up 47%. (AMA, KMA sources) This is a crisis; and

WHEREAS, a recent polling of Medicare beneficiaries reveals that scheduling to see a physician is very challenging. For example, Kentucky lost 6% of its physician workforce after COVID and the AMA is predicting a 38,000-120,000 physician shortage in 10 years. The physicians in the system are at the breaking point; and

WHEREAS, using the 340B logic that saved rural hospitals (critical access hospitals), it is reasonable to promote similar lawmaking. Allowing physicians to share in the profit from their EMR investment and daily work product will help physicians remain in Medicare and assist with recruitment; and

WHEREAS, if MIPS is eliminated, as some in the US Doctor's Caucus hope, then allowing a profit-sharing system will preserve sharing of data for research, especially images and other structured diagnostic data, and it may be the only course of action that can save the current research (Registry) model if wholesale reform occurs; and

WHEREAS, this initiative will cost taxpayers nothing, it does not include a mandate, and has similar precedent in Congress to save Rural Hospitals; and

WHEREAS, this proposal is not predicted to be a windfall in terms of individual physician revenue, because data for any given research project comes from such a wide array of practices, but it represents something positive in an otherwise bleak Medicare future, it encourages Physician participation, and it is fair; now, therefore, be it

RESOLVED, that KMA use its resources to lobby and promote this proposed solution as set forth below to our US representatives: as an amendment to HIPAA.

42 US Code Section 17935:

> (B) The purpose of the exchange is for research (as described in sections 164.501 and 164.512(i) of title 45, Code of Federal Regulations) or an exchange to a data registry where it will be de-identified and available for research purposes and the price charged reflects the costs of preparation and transmittal of the data for such purpose and, in order to encourage participation in such activities, compensation for professional services, not to exceed thirty percent (30%) of the commercial fair market value of the data and imagery. Compensation for professional services will be limited to entities participating in Medicare and Medicaid. *(Changes are highlighted)*