Whereas, The Health Insurance Portability and Accountability Act (HIPAA) placed “limitations on the sale of medical information to third parties for marketing purposes” and prevents medical information from being disclosed unless permitted or required;1,2,3 and

Whereas, Secondary use of health data entails the use of protected health information (PHI) outside of direct healthcare delivery including strictly commercial activities;4 and

Whereas, Under HIPAA, patient consent is not required to use and disclose PHI for treatment, payment, and healthcare operations (TPO); meanwhile, patient authorization is required when “voluntary consent is not sufficient to permit a use or disclosure of protected health information” which largely consists of any use outside of TPO, unless an exception applies;4 and

Whereas, HIPAA does not apply after data is de-identified nor does it prohibit selling or sharing of de-identified data without prior patient authorization for “research, public health, law enforcement, judicial proceedings, and other ‘public interest and benefit activities’”;2,5,6,7,8 and

Whereas, The extent to which patient data collection and use for purposes not directly related to patient care and public health such as for pure commercial intent is not well understood or regulated;9,10 and

Whereas, A multimillion-dollar industry has been established based on sales of patient health-related information;10 and

Whereas, In US courts, transactions involving de-identified patient data irrespective of their purpose have come to be labeled as expressions of free speech;11,12 and

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5 Cornell Law Legal Information Institute. 45 CFR 164.512 Uses and disclosures for which an authorization or opportunity to agree or object is not required. https://www.law.cornell.edu/cfr/text/45/164.512%0D. Published 2016.
8 Department of Health and Human Services. May a health information organization (HIO), acting as a business associate of a HIPAA covered entity, de-identify information and then use it for its own purposes? 2008. https://www.hhs.gov/hipaa/for-professionals/faq/544/may-a-health-information-organization-de-identify-information/index.html.
Whereas, PHI ownership rights, whether it be the patient, provider, government or another entity, is unclear and has yet to be formally settled; and

Whereas, As individuals continue to divulge personal information in areas outside of healthcare, it becomes easier to consolidate data and identify those individuals in aggregated pools of anonymized health data; and

Whereas, AMA Policy H-315.983 states that only de-identified and/or aggregate data should be used for "business decisions," including sales, mergers, and similar business transactions when ownership or control of medical records changes hands; and

Whereas, AMA Code of Ethics Section 3.2.4 Paragraph 2 states, “Disclosing information to third parties for commercial purposes without consent undermines trust, violates principles of informed consent and confidentiality, and may harm the integrity of the patient-physician relationship”; and

Whereas, AMA Code of Ethics Section 3.2.4 enables the release of patient information so long as it is de-identified and only recommends that patients be informed of the impending release without providing patients an avenue to prevent third parties from utilizing their PHI for commercial purposes; and

Whereas, AMA Code of Ethics Section 3.2.4 is conflicting as it emphasizes patient consent in Paragraph 2 while Paragraph 3 immediately defers to patients only needing to be informed about use of their de-identified information rather than providing consent; and

Whereas, AMA Code of Ethics Section 3.2.4 may conflict with HIPAA in that patient authorization, rather than consent, is sometimes mandated for release of identifiable patient information to third parties for reasons other than TPO; and

Whereas, A lack of accountability and transparency on how a patient’s own health data will be used beyond their immediate care undermines both the informed consent process and the patient-physician relationship, and impairs future efforts in healthcare, research, and public health; therefore be it

RESOLVED, That our American Medical Association study the handling of de-identified patient information and report findings and recommendations back to the AMA House of Delegates. (Directive to Take Action)

Fiscal Note: not yet determined

Date Received: 04/26/18
