AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: xxx
(June 2021)

Introduced by: Steven Chen, MD

Subject: Preventing Inappropriate Use of Patient Protected Medical Information in the Vaccination Process

Referred to: PPPS Reference Committee
(xxxx, MD, Chair)

WHEREAS, Retail pharmacies have played a key role in expanding access to COVID-19 vaccination; and

WHEREAS, Many larger retail pharmacies are collecting a significant amount of medical history and contact information from patients seeking to schedule COVID-19 vaccinations, sometimes even for those merely seeking to see if an appointment is available; and

WHEREAS, Some larger retail pharmacy chains see this as an opportunity to recruit patients to utilize their retail health clinics for routine visits in competition with a patient's medical home[1]; and

WHEREAS, These chains are indicating to investors that they plan to utilize this information to "expand our customer base while deepening relationships with current customers" and to make "measurable and important progress with our strategy as a health services company" including using such information for future marketing to these patients or recruiting patients to their associated retail health clinics and integrated health platforms[2]; and

WHEREAS, Some scheduling assistant websites or private providers asked about various medical conditions to assess eligibility priority and may have retained the information; and

WHEREAS, A coalition of digital privacy advocates have raised concerns that HIPAA may not necessarily cover data that is given for vaccination scheduling[3]; and

WHEREAS, Privacy concerns may deter patients from obtaining vaccines; therefore be it

RESOLVED, That our American Medical Association advocate to prohibit the use of patient/customer information collected by retail pharmacies for COVID-19 vaccination scheduling and/or the vaccine administration process for commercial marketing or future patient recruiting purposes, especially any targeting based on medical history or conditions (New HOD Policy); and be it further

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[1] Comments by Karen Lynch (CEO) during CVS 4th quarter, 2020 earnings call. Transcript accessible at: https://www.fool.com/earnings/call-transcripts/2021/02/16/cvs-health-cvs-q4-2020-earnings-call-transcript/

[2] Terlep, Sharon. "CVS, Walgreens Look for Big Data Reward From Covid-19 Vaccinations." Wall Street Journal, March 2, 2021. Available at: https://www.wsj.com/articles/cvs-walgreens-look-for-big-data-reward-from-covid-19-vaccinations-11614681180

[3] Electronic Privacy Information Center coalition letter to Attorney General Karl A. Racine. Available at: https://epic.org/privacy/medical/coalition-letter-DC-pharmacy-data-collection-040221.pdf

RESOLVED, That our AMA oppose the sale of medical history data and contact information accumulated through the scheduling or provision of government-funded vaccinations to third parties for use in marketing or advertising (New HOD Policy).

Fiscal Note: Not yet determined

Received: 4/20/21

RELEVANT AMA POLICY

Code of Medical Ethics: 3.1.1 Privacy in Health Care

Protecting information gathered in association with the care of the patient is a core value in health care. However, respecting patient privacy in other forms is also fundamental, as an expression of respect for patient autonomy and a prerequisite for trust.

Patient privacy encompasses a number of aspects, including personal space (physical privacy), personal data (informational privacy), personal choices including cultural and religious affiliations (decisional privacy), and personal relationships with family members and other intimates (associational privacy).

Physicians must seek to protect patient privacy in all settings to the greatest extent possible and should:

(a) Minimize intrusion on privacy when the patient's privacy must be balanced against other factors.

(b) Inform the patient when there has been a significant infringement on privacy of which the patient would otherwise not be aware.

(c) Be mindful that individual patients may have special concerns about privacy in any or all of these areas.

AMA Principles of Medical Ethics: I,IV

The Opinions in this chapter are offered as ethics guidance for physicians and are not intended to establish standards of clinical practice or rules of law.

Citation: Issued: 2016

Police, Payer, and Government Access to Patient Health Information H-315.975

(1) Our AMA advocates vigorously, with respect to the final privacy rule or other privacy legislation, to define "health care operations" narrowly to include only those activities and functions that are routine and critical for general business operations and that cannot reasonably be undertaken with de-identified information.

(2) Our AMA advocates vigorously, with respect to the final privacy rule or other privacy legislation, that the Centers for Medicare & Medicaid Services (CMMS) and other payers shall have access to medical records and individually identifiable health information solely for billing and payment purposes, and routine and critical health care operations that cannot reasonably be undertaken with de-identified health information.

(3) Our AMA advocates vigorously, with respect to the final privacy rule or other privacy legislation, that CMMS and other payers may access and use medical records and individually identifiable health information for non-billing, non-payment purposes and non-routine, non-critical health care operations that cannot reasonably be undertaken with de-identified health information, only with the express written consent of the patient or the patient's authorized representative, each and every time, separate and apart from blanket consent at time of enrollment.

(4) Our AMA advocates vigorously, with respect to the final privacy rule or other privacy legislation that no government agency, including law enforcement agencies, be permitted access to medical records or individually identifiable health information (except for any discretionary or mandatory disclosures made by physicians and other health care providers pursuant to ethical guidelines or to comply with applicable state or federal reporting laws) without the express written consent of the patient, or a court order or warrant permitting such access.

(5) Our AMA continues to strongly support and advocate a minimum necessary standard of disclosure of individually identifiable health information requested by payers, so that the information necessary to accomplish the intended purpose of the request be determined by physicians and other health care providers, as permitted under the final privacy rule.

Citation: Res. 246, A-01; Reaffirmed: I-01; Reaffirmed: A-02; Reaffirmed: BOT Rep. 19, I-06; Reaffirmed: A-07; Reaffirmed: BOT Rep. 19, A-07; Reaffirmed: BOT Rep. 22, A-17

Patient Privacy and Confidentiality H-315.983

1. Our AMA affirms the following key principles that should be consistently implemented to evaluate any proposal regarding patient privacy and the confidentiality of medical information: (a) That there exists a basic right of patients to privacy of their medical information and records, and that this right should be explicitly acknowledged; (b) That patients' privacy should be honored unless waived by the patient in a meaningful way or in rare instances when strong countervailing interests in public health or safety justify invasions of patient privacy or breaches of confidentiality, and then only when such invasions or breaches are subject to stringent safeguards enforced by appropriate standards of accountability; (c) That patients' privacy should be honored in the context of gathering and disclosing information for clinical research and quality improvement activities, and that any necessary departures from the preferred practices of obtaining patients' informed consent and of de-identifying all data be strictly controlled; (d) That any information disclosed should be limited to that information, portion of the medical record, or abstract necessary to fulfill the immediate and specific purpose of disclosure; and (e) That the Health Insurance Portability and Accountability Act of 1996 (HIPAA) be the minimal standard for protecting clinician-patient privilege, regardless of where care is received.

2. Our AMA affirms: (a) that physicians and medical students who are patients are entitled to the same right to privacy and confidentiality of personal medical information and medical records as other patients, (b) that when patients exercise their right to keep their personal medical histories confidential, such action should not be regarded as fraudulent or inappropriate concealment, and (c) that physicians and medical students should not be required to report any aspects of

their patients' medical history to governmental agencies or other entities, beyond that which would be required by law.

3. Employers and insurers should be barred from unconsented access to identifiable medical information lest knowledge of sensitive facts form the basis of adverse decisions against individuals. (a) Release forms that authorize access should be explicit about to whom access is being granted and for what purpose, and should be as narrowly tailored as possible. (b) Patients, physicians, and medical students should be educated about the consequences of signing overly-broad consent forms. (c) Employers and insurers should adopt explicit and public policies to assure the security and confidentiality of patients' medical information. (d) A patient's ability to join or a physician's participation in an insurance plan should not be contingent on signing a broad and indefinite consent for release and disclosure.

4. Whenever possible, medical records should be de-identified for purposes of use in connection with utilization review, panel credentialing, quality assurance, and peer review.

5. The fundamental values and duties that guide the safekeeping of medical information should remain constant in this era of computerization. Whether they are in computerized or paper form, it is critical that medical information be accurate, secure, and free from unauthorized access and improper use.

6. Our AMA recommends that the confidentiality of data collected by race and ethnicity as part of the medical record, be maintained.

7. Genetic information should be kept confidential and should not be disclosed to third parties without the explicit informed consent of the tested individual.

8. When breaches of confidentiality are compelled by concerns for public health and safety, those breaches must be as narrow in scope and content as possible, must contain the least identifiable and sensitive information possible, and must be disclosed to the fewest possible to achieve the necessary end.

9. Law enforcement agencies requesting private medical information should be given access to such information only through a court order. This court order for disclosure should be granted only if the law enforcement entity has shown, by clear and convincing evidence, that the information sought is necessary to a legitimate law enforcement inquiry; that the needs of the law enforcement authority cannot be satisfied by non-identifiable health information or by any other information; and that the law enforcement need for the information outweighs the privacy interest of the individual to whom the information pertains. These records should be subject to stringent security measures.

10. Our AMA must guard against the imposition of unduly restrictive barriers to patient records that would impede or prevent access to data needed for medical or public health research or quality improvement and accreditation activities. Whenever possible, de-identified data should be used for these purposes. In those contexts where personal identification is essential for the collation of data, review of identifiable data should not take place without an institutional review board (IRB) approved justification for the retention of identifiers and the consent of the patient. In those cases where obtaining patient consent for disclosure is impracticable, our AMA endorses the oversight and accountability provided by an IRB.

11. Marketing and commercial uses of identifiable patients' medical information may violate principles of informed consent and patient confidentiality. Patients divulge information to their

physicians only for purposes of diagnosis and treatment. If other uses are to be made of the information, patients must first give their uncoerced permission after being fully informed about the purpose of such disclosures

12. Our AMA, in collaboration with other professional organizations, patient advocacy groups and the public health community, should continue its advocacy for privacy and confidentiality regulations, including: (a) The establishment of rules allocating liability for disclosure of identifiable patient medical information between physicians and the health plans of which they are a part, and securing appropriate physicians' control over the disposition of information from their patients' medical records. (b) The establishment of rules to prevent disclosure of identifiable patient medical information for commercial and marketing purposes; and (c) The establishment of penalties for negligent or deliberate breach of confidentiality or violation of patient privacy rights.

13. Our AMA will pursue an aggressive agenda to educate patients, the public, physicians and policymakers at all levels of government about concerns and complexities of patient privacy and confidentiality in the variety of contexts mentioned.

14. Disclosure of personally identifiable patient information to public health physicians and departments is appropriate for the purpose of addressing public health emergencies or to comply with laws regarding public health reporting for the purpose of disease surveillance.

15. In the event of the sale or discontinuation of a medical practice, patients should be notified whenever possible and asked for authorization to transfer the medical record to a new physician or care provider. 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.

16. The most appropriate jurisdiction for considering physician breaches of patient confidentiality is the relevant state medical practice act. Knowing and intentional breaches of patient confidentiality, particularly under false pretenses, for malicious harm, or for monetary gain, represents a violation of the professional practice of medicine.

17. Our AMA Board of Trustees will actively monitor and support legislation at the federal level that will afford patients protection against discrimination on the basis of genetic testing.

18. Our AMA supports privacy standards that would require pharmacies to obtain a prior written and signed consent from patients to use their personal data for marketing purposes.

19. Our AMA supports privacy standards that require pharmacies and drug store chains to disclose the source of financial support for drug mailings or phone calls.

20. Our AMA supports privacy standards that would prohibit pharmacies from using prescription refill reminders or disease management programs as an opportunity for marketing purposes.

21. Our AMA will draft model state legislation requiring consent of all parties to the recording of a physician-patient conversation.

Citation: BOT Rep. 9, A-98; Reaffirmed: I-98; Appended: Res. 4 and Reaffirmed: BOT Rep. 36, A-99; Appended: BOT Rep. 16 and Reaffirmed: CSA Rep. 13, I-99; Reaffirmed: A-00; Reaffirmed: Res. 246 and 504 and Appended Res. 504 and 509, A-01; Reaffirmed: BOT Rep. 19, I-01; Appended: Res. 524, A-02; Reaffirmed: Sub. Res. 206, A-04; Reaffirmed: BOT Rep.

24, I-04; Reaffirmed: BOT Rep. 19, I-06; Reaffirmed: A-07; Reaffirmed: BOT Rep. 19, A-07; reaffirmed: CEJA Rep. 6, A-11; Reaffirmed in lieu of Res. 705, A-12; Reaffirmed: BOT Rep. 17, A-13; Modified: Res. 2, I-14; Reaffirmed: A-17; Modified: BOT Rep. 16, A-18; Appended: Res. 232, A-18; Reaffirmed: I-18