

AMERICAN MEDICAL ASSOCIATION RESIDENT AND FELLOW SECTION

Resolution: 11
(I-26)

Introduced by: Anthony Sean de Leon, MD

Subject: Health Privacy, Research, and Stigmatized Conditions like Autism

Referred to: Reference Committee

1 Whereas, autism is a neurodivergent biopsychosocial condition with a wide range of
2 manifestations and severity revolving around difficulties with social communication and
3 repetitive behaviors; and
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5 Whereas, autism is a highly stigmatized condition¹; and
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7 Whereas, the Department of Health and Human Services (HHS) Secretary and the National
8 Institutes of Health (NIH) Director proposed a platform that would allow researchers looking into
9 the root causes of autism by examining insurance claims, electronic medical records, and
10 wearable devices including smartwatches²; and
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12 Whereas, HHS will draw records from the Centers for Medicare and Medicaid Services and the
13 NIH to supply this platform; and
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15 Whereas, the HHS Secretary's underlying motive for this platform stems from claims that do not
16 have any strong scientific evidence or consensus such as the association of autism with
17 vaccination, and that vaccines are responsible for a rapid rise in autism diagnoses in the US;
18 and
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20 Whereas, it is not clear exactly what this platform will research, with a vague mission "to
21 uncover the root causes of autism and other chronic diseases"; and
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23 Whereas, *KFF Health* reported on June 7, 2026, that the HHS Secretary is using health
24 information exchange systems (HIES) and public health entities—which have historically
25 facilitated interoperability and monitored infectious disease—to conduct autism-centered
26 research^{3,4}; and
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28 Whereas, HES are state-managed with a trove of contractual agreements dictating who can
29 access such information and for what purposes; and
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31 Whereas, Nebraska is the first state to start sharing its HES with the federal government for
32 autism research, and subsequently won several Centers for Disease Control and Prevention
33 (CDC) grants last December; and
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35 Whereas, data gleaned from insurance claims intended for one purpose could be
36 misappropriated for another use (e.g., from investigating gastrointestinal symptoms in autistic
37 children to vaccine harm studies); and
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39 Whereas, other state governments, including Illinois, have issued executive orders aimed at
40 protecting the privacy of autistic patients and persons with autism; and

Whereas, autism advocates fear that overemphasis on pathophysiology would divert needed research funding and resources away from more impactful interventions like caregiver support, psychosocial development, and resolution of health disparities in people with autism and autistic people⁴⁻⁷; and

Whereas, a well-informed research agenda designed for and by autistic people, researchers, and physicians in collaboration with HHS is far more productive than leaving these stakeholders out⁸; and

Whereas, our AMA does advocate for general patient privacy in H-315.983, but stronger accountability of research into a stigmatized condition like autism is needed, especially on health information that was originally only collected for treatment and prevention; therefore be it

RESOLVED, that our American Medical Association (AMA) opposes the data collection of sensitive health information on stigmatizing conditions like autism that was not explicitly and originally intended for research; and be it further

RESOLVED, that our AMA supports the inclusion of autistic people and people with autism in the planning, development, execution, and dissemination of autism research; and be it further

RESOLVED, that this resolution be immediately forwarded to the AMA House of Delegates at the 2026 Interim Meeting.

Fiscal Note: Minimal

References:

1. Kang J, Baes N, Wu A, Haslam N. Who you are or what you have: historical trends in books and news media. *PLoS Ment Health*. 3(9): e0000684. Published doi.org/10.1371/journal.pmen.0000684
2. Stolberg SG. Kennedy announces new database for research into 'root causes' of autism. *The New York Times*. Published June 7, 2026. Accessed August 31, 2026. <https://www.nytimes.com/2025/05/07/us/politics/rfk-jr-autism-cause-database.html>
3. Science Insights. What is health information exchange and how it works. Published May 1, 2026. Accessed September 19, 2026. <https://scienceinsights.org/what-is-health-information-exchange-and-how-it-works/>
4. Seitz A, Tahir D. RFK Jr. seeks to peek at Americans' Medical records for clues on autism and vaccines. *MedPage Today*. Published June 7, 2026. Accessed August 31, 2026.
5. Mandell DS. Why we should be concerned about an autism registry. *JAMA*. Published September 29, 2025. Accessed September 16, 2026. doi:10.1001/jamapediatrics.2025.3459
6. HHS walks back "autism registry" plans. Published April 25, 2025. Accessed September 19, 2026. <https://autisticadvocacy.org/2025/04/hhs-walks-back-autism-registry-plans/>
7. Leveille V. Disability rights and privacy advocates raise concern with proposed autism "registry". *ACLU*. Published May 12, 2025. Accessed September 16, 2026. <https://www.aclu.org/press-releases/disability-rights-and-privacy-advocates-raise-concerns-with-proposed-autism-registry>
8. Haar T, Brownlow C, Hall G, et al. 'We have so much to offer': Community members' perspectives on autism research. *Autism*. 2025;29(9):2254-2267. doi:10.1177/13623613241248713

RELEVANT AMA POLICY

Caring for Neurodivergent Patients H-90.962

1. Our American Medical Association supports research toward the evaluation and the development of interventions and programs for autistic individuals.
2. Our AMA will work with relevant stakeholders to advocate for a comprehensive spectrum of primary and specialty care that recognizes the diversity and personhood of individuals who are neurodivergent, including people with autism.
3. Our AMA advocates for peer reviewed, evidence-based guidance for states on innovative health systems solutions to reduce specific barriers to the diagnosis and treatment of autism, including complex care coordination in the medical home by primary care team members trained in the diagnosis and treatment of autism. [Res. 706, A-23; Appended: Res. 902, I-25]

Standardizing Coverage of Evidence-Based Treatments for Neurodivergent Individuals H-185.921

Our American Medical Association supports coverage and reimbursement for evidence-based treatments and services for neurodivergent individuals, including Autism Spectrum Disorder.
[Res. 123, A-19; Modified: Res. 706, A-23]

Early Intervention for Individuals with Developmental Delay H-90.969

1. Our AMA will continue to work with appropriate medical specialty societies to educate and enable physicians to identify children with developmental delay, autism and other developmental disabilities, and to urge physicians to assist parents in obtaining access to appropriate individualized early intervention services.
2. Our AMA supports a simplified process across appropriate government agencies to designate individuals with intellectual disabilities as a medically underserved population.

[CCB/CLRPD Rep. 3, A-14; Reaffirmed: Res. 315, A-17]

Patient Privacy and Confidentiality H-315.983

1. Our American Medical Association 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;
 - 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.

[BOT Rep. 9, A-98; Reaffirmation I-98; Appended: Res. 4, and Reaffirmed: BOT Rep. 36, A-99; Appended: BOT Rep. 16 and Reaffirmed: CSA Rep. 13, I-99; Reaffirmation 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; Reaffirmation 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; Reaffirmation: A-17; Modified: BOT Rep. 16, A-18; Appended: Res. 232, A-18; Reaffirmation: I-18; Reaffirmed: Res. 219; A-21; Reaffirmed: Res. 229, A-21; Reaffirmed: BOT Rep. 12, I-21; Reaffirmed: BOT Rep. 22, A-22; Reaffirmation: A-23, Reaffirmed: CSAPH Rep. 08, A-24; Reaffirmed: Res. 222; A-26]