Reference Committee on Amendments to Constitution and Bylaws

BOT Report(s)

- 02 New Specialty Organizations Representation in the House of Delegates
- 26 Research Handling of De-Identified Patient Information

CC&B Report(s)

01 Clarification to the Bylaws: Delegate Representation, Registration and Credentialing

CEJA Report(s)

- 01 Competence, Self-Assessment and Self-Awareness
- 02 Physician Assisted Suicide
- 03 CEJA's Sunset Review of 2009 House Policies

Resolution(s)

- 001 Opposing Attorney Presence at and/or Recording of Independent Medical Examinations
- 002 Addressing Existential Suffering in End-of-Life Care
- 003 Conforming Sex and Gender Designation on Government IDs and Other Documents
- 004 Reimbursement for Care of Practice Partner Relatives
- 005 Right for Gamete Preservation Therapies
- 006 Use of Person-Centered Language
- 007 Delegation of Informed Consent
- 008# Preventing Anti-Transgender Violence
- 009# References to Terms and Language in Policies Adopted to Protect Populations from Discrimination and Harassment
- 010# Covenants not to Compete
- 011# Mature Minor Consent to Vaccinations
- 012# Improving Body Donation Regulation
- 013# Opposing Office of Refugee Resettlement's Use of Medical and Psychiatric Records for Evidence in Immigration Court
- 014# Disclosure of Funding Sources and Industry Ties of Professional Medical Associations and Patient Advocacy Organizations
- 015# Opposing Mandated Reporting of People Who Question Their Gender Identity
- 016# Sexual and Gender Minority Populations in Medical Research
- 017# National Guidelines for Guardianship
- 018# Support for Requiring Investigations into Deaths of Children in Foster Care
- 019# Opposition to Requirements for Gender-Based Medical Treatments for Athletes
- 020# Changes to E-5.7, "Physician-Assisted Suicide"
- 021# Health, In All Its Dimensions, Is a Basic Right
- 022# Opposition to Involuntary Civil Commitment for Substance Use Disorder

REPORT OF THE BOARD OF TRUSTEES

B of T Report 2-A-19

Subject:	New Specialty Organizations Representation in the House of Delegates	
Presented by:	Jack Resneck, Jr., MD, Chair	
Referred to:	Reference Committee on Amendments to Constitution and Bylaws (William Reha, MD, MBA, Chair)	
applications of the Cytopathology for Association (AM)	ustees (BOT) and the Specialty and Service Society (SSS) considered the ne American Academy of Sleep Medicine and the American Society of or national medical specialty organization representation in the American Medical IA) House of Delegates (HOD). The applications were first reviewed by the AMA mittee and presented to the SSS Assembly for consideration.	
* *	were considered using criteria developed by the Council on Long Range Planning t and adopted by the HOD (Policy G-600.020). (Exhibit A)	
AMA. That infor	eking admission were asked to provide appropriate membership information to the rmation was analyzed to determine AMA membership, as required under criterion this information is attached to this report as Exhibit B.	
	nizations must submit a letter of application in a designated format. This format nentioned guidelines followed by each organization's explanation of how it meets ria.	
	is eligible for admission to the HOD, it must participate in the SSS for three years. In shave actively participated in the SSS for more than three years.	
indicated that the	aterials and discussion during the SSS meeting at the 2018 Interim Meeting e American Academy of Sleep Medicine and the American Society of neet the criteria for representation in the HOD.	
RECOMMENDA	ATION	
Therefore, the Board of Trustees recommends that the American Academy of Sleep Medicine and the American Society of Cytopathology be granted representation in the AMA House of Delegates and that the remainder of the report be filed. (Directive to Take Action)		

Fiscal Note: Less than \$500 to implement.

APPENDIX

Exhibit A

GUIDELINES FOR REPRESENTATION IN & ADMISSION TO THE HOUSE OF DELEGATES:

National Medical Specialty Societies

- 1) The organization must not be in conflict with the constitution and bylaws of the American Medical Association by discriminating in membership on the basis of race, religion, national origin, sex, or handicap.
- 2) The organization must (a) represent a field of medicine that has recognized scientific validity; and (b) not have board certification as its primary focus, and (c) not require membership in the specialty organization as a requisite for board certification.
- 3) The organization must meet one of the following criteria:
 - 1,000 or more AMA members;
 - At least 100 AMA members and that twenty percent (20%) of its physician members who are eligible for AMA membership are members of the AMA; or
 - Have been represented in the House of Delegates at the 1990 Annual Meeting and that twenty percent (20%) of its physician members who are eligible for AMA membership are members of the AMA.
- 4) The organization must be established and stable; therefore, it must have been in existence for at least 5 years prior to submitting its application.
- 5) Physicians should comprise the majority of the voting membership of the organization.
- 6) The organization must have a voluntary membership and must report as members only those who are current in payment of dues, have full voting privileges and are eligible to hold office.
- 7) The organization must be active within its field of medicine and hold at least one meeting of its members per year.
- 8) The organization must be national in scope. It must not restrict its membership geographically and must have members from a majority of the states.
- 9) The organization must submit a resolution or other official statement to show that the request is approved by the governing body of the organization.
- 10) If international, the organization must have a US branch or chapter, and this chapter must be reviewed in terms of all of the above guidelines.

RESPONSIBILITIES OF NATIONAL MEDICAL SPECIALTY ORGANIZATIONS

- 1. To cooperate with the AMA in increasing its AMA membership.
- 2. To keep its delegate to the House of Delegates fully informed on the policy positions of the organizations so that the delegate can properly represent the organization in the House of Delegates.
- 3. To require its delegate to report to the organization on the actions taken by the House of Delegates at each meeting.
- 4. To disseminate to its membership information to the actions taken by the House of Delegates at each meeting.
- 5. To provide information and data to the AMA when requested.

Exhibit B - Summary Membership Information

Organization

AMA Membership of Organization's Total Eligible Membership

American Academy of Sleep Medicine

1,202 of 5,185 (23%)

American Society of Cytopathology

286 of 1,371 (21%)

REPORT 26 OF THE BOARD OF TRUSTEES (A-19) Research Handling of De-Identified Patient Information (Reference Committee on Amendments to Constitution and Bylaws)

EXECUTIVE SUMMARY

At the 2018 Annual Meeting, Policy D-315.975, "Research Handling of De-Identified Patient Information," was adopted by the House of Delegates. This policy directs the American Medical Association (AMA) to study the handling of de-identified patient data and report the findings and recommendations to the House of Delegates at the 2019 Annual Meeting. This report outlines appropriate and inappropriate use of de-identified patient data, perspectives from stakeholders in organized medicine, potential ethical concerns of the commercial use of such data, regulatory implications, and recommendations for the future use of de-identified patient data

Protected health information (PHI) includes many common identifiers (e.g., name, address, birth date, Social Security Number) when they can be associated with patient health information. The HIPAA Privacy Rule sets limits and conditions on the uses and disclosures that may be made of such information without patient authorization. Security of PHI safeguards patients from the risk of their data being released or used in manners that could result in discrimination, stigmatization, or embarrassment. However, the use, sale, or distribution of de-identified patient data is not prohibited under HIPAA, since once PHI is de-identified in accordance with the HIPAA Privacy Rule, it is no longer considered PHI and, thus, may be used and disclosed by a covered entity or health information organization (HIO) for any purpose.

REPORT OF THE BOARD OF TRUSTEES

B of T Report 26-A-19

Subject: Research Handling of De-Identified Patient Information

Presented by: Jack Resneck, Jr., MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

INTRODUCTION

At the 2018 Annual Meeting, Policy D-315.975, "Research Handling of De-Identified Patient Information," was adopted by the House of Delegates. This policy directs the American Medical Association (AMA) to study the handling of de-identified patient data and report the findings and recommendations to the House of Delegates at the 2019 Annual Meeting. This report outlines appropriate and inappropriate use of de-identified patient data, perspectives from stakeholders in organized medicine, potential ethical concerns of the commercial use of such data, regulatory implications, and recommendations for the future use of de-identified patient data.

BACKGROUND

 Health-related information collected during the course of clinical care has always been of great interest for a number of secondary use cases, including scientific research in the academic and commercial settings, marketing for pharmaceutical and medical device companies, and a wide variety of other uses. More recently, a new and substantial interest has been raised from technology companies who seek to use patient data to build new clinical tools using machine learning and "big data." Clinical data is the topic of significant ethical guidance and regulation at both the state and federal levels, focused primarily on the appropriate use and handling of identifiable patient information. Little guidance exists, however, on the use of de-identified patient data.

A variety of entities, including provider organizations, clinical laboratories, and commercial entities such as personal genomics companies, may collect patient data intended for clinical use or to deliver genetics information, and then resell de-identified data to other entities for other purposes. For example, 23andMe, a personal genomics and biotech service, sells de-identified user data to pharmaceutical companies that use it to conduct research on various diseases. Concerns arise in that when the data is de-identified, it is no longer considered PHI and therefore patient authorization or consent for use is not required and therefore not solicited—meaning that patients are not always aware how their data is being used. For example, research using de-identified data such as biologic specimens may result in scientific knowledge that has commercial value. Proper consent for use and/or disclosure of commercial interest in this research is ideal but not always documented, sometimes resulting in legal action against physicians or researchers.

In addition, there is a perceived lack of transparency and regulation in how patients' data is being sold, distributed, or used outside of their direct health care. Risk of re-identification, which some studies have demonstrated to be possible through matching data to other publicly available data sources, is another issue related to the use of de-identified data. There are also concerns about

access to such information that is sought for marketing purposes on behalf of commercial entities that have financial interests in physicians' treatment and/or prescribing behavior. In addition, the sale of de-identified data by clinicians and provider organizations may create a real or perceived conflict of interest, which could lead to a loss of patient confidence.

What is Protected Health Information

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides extensive protections for patient data that is considered protected health information (PHI).³ PHI is information, including demographic information, which relates to an individual's past, present, or future physical or mental health or condition; the provision of health care to the individual; or the past, present, or future payment for the provision of health care to the individual, and that identifies the individual or for which there is a reasonable basis to believe can be used to identify the individual.⁴ PHI includes many common identifiers (e.g., name, address, birth date, Social Security Number) when they can be associated with the health information listed above. The HIPAA Privacy Rule sets limits and conditions on the uses and disclosures that may be made of such information without patient authorization.⁵ Security of PHI safeguards patients from the risk of their data being released or used in manners that could result in discrimination, stigmatization, or embarrassment.^{6,7} Section 164.514(a) of the HIPAA Privacy Rule establishes standards for deidentifying PHI so individuals can no longer be identified by any portion of the data. The use, sale, or distribution of de-identified patient data is not prohibited under HIPAA, since once PHI is deidentified in accordance with the HIPAA Privacy Rule, it is no longer considered PHI and, thus, may be used and disclosed by a covered entity or health information organization (HIO) for any purpose.8

In addition to regulation at the federal level, state lawmakers have exhibited a general trend toward establishing stricter guards on the use of patient data and the requirement for patient consent, some of which reflect standards set forth in the European Union's recent General Data Protection Regulation (GDPR). Some states are considering and passing laws to protect consumer privacy as it relates to the use of their personal information. For example, California in June 2018 passed the California Consumer Privacy Act of 2018 (effective January 1, 2020), which protects consumers' right to: (1) know what personal information a for-profit business has collected about them, where it was sourced from, what it is being used for, whether it is being disclosed or sold, and to whom it is being disclosed or sold; (2) "opt out" of allowing a business to sell their personal information to third parties; (3) have a business delete their personal information, with some exceptions; and (4) receive equal service and pricing from a business, even if they exercise their privacy rights under the Act. Act and pricing from a business, even if they exercise their privacy rights under the Act. California's law does not apply to information covered by HIPAA, de-identified personal data, or aggregate consumer data, however, as long as the de-identification measures meet the Act's strict standards.

What is de-identified patient data?

De-identified patient data is information about a patient or user of a health-related service that has been stripped of individually identifiable health information. Removing identifiers from PHI mitigates privacy risks to individuals and thereby supports the secondary use of data for comparative effectiveness studies, policy assessment, life sciences research, and other endeavors. Information can be de-identified by either of two means: (1) a formal determination by a qualified expert (expert determination); or (2) the removal of specified individual identifiers and an absence of actual knowledge by the covered entity that residual information could be used to identify the individual (safe harbor).

50 individual (safe harbor).51 The identifiers removed

The identifiers removed from PHI in the safe harbor method include:⁴

1 2

Names

All geographic subdivisions smaller than a state, including street address, city, county, precinct, ZIP code, and their equivalent geocodes, except for the initial three digits of the ZIP code if, according to the current publicly available data from the Bureau of the Census:

o The geographic unit formed by combining all ZIP codes with the same three initial digits contains more than 20,000 people; and

The initial three digits of a ZIP code for all such geographic units containing 20,000 or fewer people is changed to 000

10 • Ali 11 inc 12 ele

- All elements of dates (except year) for dates that are directly related to an individual, including birth date, admission date, discharge date, death date, and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older
- Telephone numbers
- Vehicle identifiers and serial numbers, including license plate numbers
- Fax numbers
 - Device identifiers and serial numbers
- Email addresses
- Web URLs
 - Social security numbers
 - Internet Protocol addresses
 - Medical record numbers
 - Biometric identifiers, including finger and voice prints
 - Health plan beneficiary numbers
 - Full-face photographs and any comparable images
- Account numbers
 - Any other unique identifying number, characteristic, or code, except as permitted
 - Certificate/license numbers

How is de-identified data used?

 De-identified data is used for research to derive information and knowledge about treatment and outcomes, as well as other patient care-related purposes. Outside of health care organizations and researchers, de-identified patient data is used by a variety of organizations and industries for various purposes, including many not related to patient care. De-identified data is sourced, collected, and used by a variety of organizations, including health care provider organizations such as hospitals or academic medical centers, and commercial enterprises such as personal genomics and biotechnology companies. Pharmaceutical manufacturers and retail pharmacies may also find use in de-identified health data to target their advertising. Health care providers use this data typically in research or the direct care of patient populations. The data can also be used to help reduce costs of care, improve treatment options, and support public health initiatives.

Machine learning is a family of methods used by some health care and data solution organizations to help predict certain outcomes and better prepare for and treat patients identified to be at risk. Machine learning models establish predictive rules using vast amounts of computing power. The more data a machine learning model has, the more complex the rules and the more accurate the predictions. However, machine learning models are vulnerable to biases induced by data that does not adequately represent the patient population, such as data collected from only one institution or one geographic region. In order to develop clinical decision support tools that can be effectively used to treat the diverse patient populations in the United States, large amounts of data are

required, and often data from many different providers across the country are required to avoid bias. This data is often sourced from de-identified or anonymized patient records. Allscripts, for example, used 50 million de-identified patient records, and the application of an advanced machine learning algorithm, to "train" its systems and further improve its clinical decision support tools. 13 Organizations like Orion Health and Precision Driven Health are using datasets like these to generate machine learning aimed at improving health care decisions, and driving operational and cost efficiencies. 12, 14 By combining multiple datasets, such as behavioral data, device use data, patient claim data and socioeconomic and geographic data, these organizations are developing advanced predictive analytics to further improve precision health care. 14 The data used for the purposes of data mining and honing machine learning algorithms are either sourced and used at the organizational level, or de-identified or anonymized when used for external research, such as the analysis done by Allscripts. Data may be sourced via publicly available de-identified datasets, databases established through collaborative research agreements, or via the purchase of bulk deidentified data, on an exclusive or non-exclusive basis. Since this technology is relatively new in the health care space its implications for patient data are not well-studied. As artificial intelligence and advanced machine learning proliferate in the health care space, the value and number of potential uses of patient health data will inevitably increase. Stakeholders should be prepared for increasing concerns about related patient privacy and data security.

Commercial entities, such as personal genomics companies, may collect data to deliver genetics information to subscribers and then subsequently sell the de-identified data to another entity for another purpose. For example, 23andMe, a genomics and biotech service, sells de-identified user data to pharmaceutical companies that use it to conduct research on various diseases. Concerns arise in that when the data is de-identified, it is no longer considered PHI and therefore patient authorization or consent for use is not required and therefore not solicited—meaning that patients are not always aware how their data is being used. For example, research using de-identified data such as biologic specimens may result in scientific knowledge that has commercial value. Proper consent for use and/or disclosure of commercial interest in this research is ideal but not always documented, sometimes resulting in legal action against physicians or researchers.

In addition, there is a perceived lack of transparency and regulation in how patients' data is being sold, distributed, or used outside of their direct health care. Risk of re-identification, which some studies have demonstrated to be possible through matching data to other publicly available data sources, is another issue related to the use of de-identified data. There are also concerns about access to such information that is sought for marketing purposes on behalf of commercial entities that have financial interests in physicians' treatment and/or prescribing behavior.

AMA POLICY

 The AMA has multiple policies expressing its recognition of the importance of data privacy and protection of PHI, as well as policies expressing commitment to ensuring safe and appropriate use of de-identified data.

Board of Trustees Report 21-A-18, "Ownership of Patient Data," outlines federal and state laws that establish who owns a patient's medical records. The report also highlights the importance of ensuring patients have appropriate access to their data and physicians have the tools and controls they need to be good stewards of their patients' information while at the same time maintaining the ability to share information to seamlessly coordinate the best care. In support of these initiatives, the AMA has actively engaged with the U.S. Department of Health and Human Services (HHS),

50 the Office of Inspector General, the Office of Civil Rights, and the Office of the National

Coordinator for Health Information Technology (ONC), and has broad policy in place covering all aspects of patient record maintenance, access and control.

AMA Policy H-315.978, "Privacy and Confidentiality," states that where possible, informed consent should be obtained before personally identifiable health information is used for any purpose. However, in those situations where specific informed consent is not practical or possible, either (1) the information should have identifying information stripped from it or (2) an objective, publicly accountable entity must determine that patient consent is not required after weighing the risks and benefits of the proposed use. Re-identification of personal health information should only occur with patient consent or with the approval of an objective, publicly accountable entity.

 AMA Policy H-315.974, "Guiding Principles, Collection and Warehousing of Electronic Medical Record Information," expresses the AMA's commitment to advocating that physicians, as trusted stewards of PHI, should be the owners of all patient claims data and de-identified aggregate data that is established and maintained by the physician practice, specifically including data stored in the electronic health record or practice management system. The policy establishes principles around the use of these data that include compliance with HIPAA, requires physician consent for analysis of the data, and requires data to remain accessible to authorized users for purposes of treatment, public health, patient safety, quality improvement, medical liability defense, and research.

AMA Policy H-315.983, "Patient Privacy and Confidentiality," states that whenever possible, medical records should be de-identified for purposes of use for utilization review, panel credentialing, quality assurance, and peer review. This policy also states our AMA will 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, and that whenever possible, de-identified data should be used for these purposes. Policy H-315-983 posits that in the event of a sale or discontinuation of a medical practice, 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. This policy includes extensive language emphasizing the AMA's commitment to protecting PHI, and that it will 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 physician 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.

In Policy H-315.975, "Police, Payer, and Government Access to Patient Health Information," the AMA commits to advocating for narrow and clearly defined bounds for the appropriate use of patient information by law enforcement, payers and government entities, for operations that cannot be reasonably undertaken with de-identified data. AMA Policy H-315.987, "Limiting Access to Medical Records," further defines who should and should not have access to this information.

The AMA's Code of Medical Ethics includes an opinion on "Access to Medical Records by Data Collection Companies." Opinion E-3.2.4 asserts that 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. The opinion further expresses that physicians who wish to permit third-party access to *specific patient information* for commercial purposes should: (a) only provide data that has been de-identified, and

(b) fully inform each patient whose record would be involved about the purpose(s) for which access would be granted. This opinion, with respect to requests for permission to allow access to or disclose a *full medical record*, prohibits disclosing identifiable information for commercial purposes *without obtaining consent* from the patient to do so.

The authors of Resolution 3-A-18, which established policy D-315.975 and is the subject of this report, expressed particular concern that this Code of Medical Ethics Opinion may contradict itself in its emphasis on informing the patient of how their de-identified data will be used and the subsequent emphasis on the importance of obtaining consent. The key difference between the two elements of the opinion lies in the description of the patient information being requested (specific, de-identified patient information vs. full medical record), thus our AMA does not agree that these statements are contradictory.

The authors also expressed that this Opinion may be in disharmony with the rules set forth in the HIPAA Privacy Rule, specifically stating that authorization, rather than consent, is sometimes mandated for the release of PHI when being requested for purposes not related to treatment, payment, or health care operations (TPO). HIPAA defines three such uses or disclosures for which written authorization of the patient is required: (1) use and disclosure of psychotherapy notes; (2) use and disclosure of PHI for marketing; and (3) any sale of PHI.

Ethical Opinion E-3.2.4 was originally issued in 1994 and updated in 1998, prior to the enactment of the HIPAA Privacy Rule, yet provides an even higher standard than the Rule with respect to requirements for consent to disclose patient data, including data that has been de-identified. With respect to authorization requirements, Opinion E-3.2.4 does not include a statement about when authorization, rather than consent, is appropriate and/or required. Guidance provided in the Code of Ethics is provided by standards of conduct that define the essentials of honorable behavior for the physician. They cover broad ethical principles and are not intended to align with law or specific regulations that may be legally enforceable. During a comprehensive eight-year modernization process that ended in 2017, the AMA *Code of Medical Ethics* was reviewed for relevance/timeliness of guidance, clarity, and consistency of guidance. Opinion E-3.2.4 was reorganized in this process, taking the HIPAA provisions into consideration during the process. Care was taken to ensure the Council on Ethical and Judicial Affairs was conservative in suggesting substantive change, doing so only where needed to ensure that guidance remains relevant in the face of changes in biomedical science and conditions of medical practice. No contradictions or points of discord with HIPAA were identified in that review.

DISCUSSION

Oversight of patient information

The use of de-identified patient data is not heavily regulated. The HIPAA Privacy Rule does not restrict the use or disclosure of de-identified health information, since it is not considered PHI.^{2, 5} HIPAA permits secondary uses of de-identified data for purposes such as public health initiatives, research, law enforcement, and other public interest endeavors.^{5, 15} In addition, commercial entities that sell or use de-identified data, such as biotech and pharmaceutical companies, are not considered covered entities under HIPAA. Through their interactions with pharmacy benefit managers, pharmacies, payers, physicians and patients, however, they are indirectly impacted by privacy rules and must structure their transactions, projects, and internal data programs such that their partners that are covered entities or business associates thereof meet data privacy

requirements under HIPAA and any other applicable standards.

Studies that use de-identified data are exempt from regulations that govern human subject research.^{2, 16} Entities that collect and use consumer data, such as pharmaceutical companies or academic institutions conducting research, should employ privacy protections into their practices, such as data security, reasonable collection limits, sound retention and disposal practices, and data accuracy to protect privacy, as guided in recommendations from the Federal Trade Commission (FTC).¹⁷ For example, Harvard University, like many academic institutions receiving federal grants, implements strict policy to govern the collection, storage and use of research data, including PHI.¹⁸ In addition to the enforcement of strict policy, all human subjects research is subject to approval by the institution's Institutional Review Board (IRB). It is the responsibility of IRBs to specify the security level for research projects they review and approve, obtain confirmation that the relevant security controls are being implemented and decide if the human subject must give consent or in the case of de-identified information, approve the research under an exempt status from obtaining the consent.

1 2

Human subject research conducted or supported by certain federal departments or agencies is governed by the Federal Policy for the Protection of Human Subjects ("Common Rule"). Revisions to the Common Rule in 2017 were adopted in response to shifts in science, technology, public engagement, and public expectations that have raised concerns about the limitations of the existing ethical framework in research. ¹⁹ The rapid pace of change in the availability, utility, and value of patient data, including PHI and de-identified data, will continue to necessitate regular reconsideration of the ethical oversight of patient data and how it is protected by researchers and other entities.

Risks and ethical concerns

There are ethical concerns about the disclosure and use of de-identified health data that are rooted in the risk of re-identification. Studies have shown that certain elements of patient records, although not exclusive or unique to individual patients, increase the risk of re-identification if not removed from individual-level data.^{20, 21} Elements such as gender, date of service, date of birth or zip code can potentially be linked back to other sources of data, such as voter registration lists, and could put the data at risk of re-identification.^{21, 22} Organizations that collect, store, transfer and distribute de-identified data should take steps to reduce this risk, such as replacing a specific date of birth or date of service with a year.

Studies have been undertaken to assess the risk of re-identification after steps have been taken to de-identify the data, and have found gaps that can put de-identified patient health data at risk of being re-identified. ^{20, 23, 24} While these findings are significant and should not be ignored, one review of some of these studies concluded that many of them were small and did not use data that was de-identified according to existing standards (those set forth in the HIPAA Privacy Rule), so caution should be taken when making generalizations based on the few cases identified in the studies.²⁵

In addition to risk of re-identification, there are general ethical concerns with the availability and use of patient health data, even if it's de-identified, without explicit authorization from patients. For example, pharmaceutical companies may use de-identified data to target marketing or advertising efforts to specific physicians, therefore influencing treatment plans for patient populations with specific diseases or conditions. Accountable Care Organizations (ACOs), as business associates of the ACO participants or a covered entity, may use de-identified data to analyze quality measures, population risk scores and patient behaviors. Other for-profit entities may use de-identified data for the development of new technology or clinical innovations. These sales of patient records for profit by provider organizations may raise concerns from the public that providers have an ulterior

- 1 motive for collecting their data during clinical encounters. In addition, patient record licensing
- 2 contracts with exclusive rights may raise questions about the appropriate stewardship of patient
- data, as such exclusive contracts may be seen to benefit specific licensees at the expense of others,
- 4 rather than enabling research and product development across the entire marketplace.

Consent and authorization

Issues that arise in the potential risks of patient data use can be mitigated by proactively obtaining appropriate authorization or consent from patients for the use of their data. These issues primarily apply to PHI covered under HIPAA, however, and not de-identified data. The HIPAA Privacy Rule permits, but does not require, a covered entity voluntarily to obtain patient consent for uses and disclosures of PHI for TPO. Covered entities that decide to obtain consent have complete discretion to design a process that best suits their needs. By contrast, an authorization is required by the Privacy Rule for most uses and disclosures of PHI not otherwise allowed by the Rule. Where the Privacy Rule requires patient authorization, voluntary consent is not sufficient to permit a use or disclosure of PHI. An authorization is a detailed document that gives covered entities permission to use PHI for specified purposes (e.g., sale or marketing of PHI) or to disclose PHI to a third party specified by the individual. An authorization must include a number of elements, including a description of the PHI to be used and disclosed, the person authorized to make the use or disclosure, the person to whom the covered entity may make the disclosure, an expiration date, and, in some cases, the purpose for which the information may be used or disclosed.²⁷

PHI may be used and disclosed for research without an authorization in limited circumstances: (1) Under a waiver of the authorization requirement; (2) as a limited data set with a data use agreement; (3) preparatory to research; and (4) for research on decedents' information. Limited data sets exclude 16 categories of direct identifiers, rather than the 18 identifiers removed in deidentified data. The information in a limited data set is considered PHI and its use or disclosure requires a data use agreement between the covered entity and the entity that will receive or use the data.

Non-covered entities that use de-identified health data for purposes such as genomics services or research are not regulated under HIPAA, but most have policies and procedures in place to protect the privacy of their subscribers or participants, and to ensure transparency in the use of the data. 23andMe, for example, obtains personal information from its subscribers and through its service identifies genetic information that is stored within its databases. According to its Privacy Policy, 23andMe "implements physical, technical, and administrative measures to prevent unauthorized access to or disclosure of your information, to maintain data accuracy, to ensure the appropriate use of information, and otherwise safeguard your Personal Information." Subscribers can voluntarily consent to allow their information to be used in research, and can also choose what level of deidentified data they consent for use. 23andMe stores and allows access to both aggregate and individual level data to third-party service providers such as marketing and analytics organizations and targeted advertising service providers that contribute to the service provided by 23andMe. It also sells de-identified user data to pharmaceutical companies for the purposes of research.

Other entities may use anonymous, de-identified data in manners that are legal but may be perceived as ethically questionable since they may not have obtained patient consent for the use of the data. For example, a startup artificial intelligence business, funded by executives at a cancer center, has received exclusive access to the cancer center's database of millions of tissue slides.²⁹ The cancer center holds an equity stake in the organization along with two of its top leaders, and other board members are initial investors in the new venture. The company's leadership indicated that some patients had provided consent for the use of their data, others did not and their data was

subsequently stripped of its identifying factors. Still, pathologists at the cancer center, and their patients, have expressed concern about the potential conflict of interest in the cancer center leadership's relationship with the startup, as well as the use of patient data for a profit-driven venture. In this case, it was reported that the enterprise had been reviewed and approved by an IRB. ²⁹

1 2

Standards and guidance

ONC publishes the "Guide to Privacy and Security of Electronic Health Information" to help physicians, other health care providers and practices work to comply with federal requirements in collecting, storing and using patients' data.³⁰

In addition to the policy set by the AMA and the guidance provided in the AMA *Code of Medical Ethics*, other physician and health care organizations provide guidelines and standards on the use of de-identified patient data. For example, the American Academy of Family Physicians published a "Data Stewardship" policy that facilitates the appropriate collection, storage, transmission, analysis, and reporting of de-identified patient data.³¹ This policy includes guidance on establishing and maintaining a proper patient and physician consent process, as well as the appropriate use of data by third parties and policies that establish requirements for third party use.

The American College of Physicians (ACP) policy encourages clinical entities and physicians to publish electronically their policies and procedures for sharing patient data and ensuring privacy. ACP's policy also states that in keeping with HIPAA, patients should know what information exists about them, its purpose, who can access and use it, and where it resides. While ACP supports the use of appropriately de-identified patient data for socially important activities, such as population health efforts and retrospective research, it does recommend tighter controls on the risks of re-identification of de-identified data.³²

CONCLUSION

 Access to de-identified patient data is important for the future of health care. Its benefits to the field of research have significant implications for our ability to make progress in refining the practice of medicine, reducing health care costs, reducing and preventing chronic disease, identifying cures for deadly conditions, and much more. In practice-level interventions, de-identified data can help practice administrators recognize patterns and gaps in processes and treatment plans across clinicians. In the genomics and biotechnology fields the study of patient data, stripped of identifying factors, can contribute to global innovation in medical technology and pharmaceutical solutions. There are numerous ways in which the use of de-identified patient data contributes to the continuum of improvement that is much needed across health care.

Its use does not come without risks, however. In 1951, the development of the HeLa cell line led to many significant research accomplishments in medicine. However, the lack of patient consent in the development of the cell line raises serious ethical concerns, which were further compounded by the commercial use of the cell line for profit, which was not shared with the patient or her family. Though in recent times, substantial effort has been made to correct this historical wrong by the National Institutes of Health and other organizations, much of the harm done to patients who's clinically obtained samples were used without consent can never be undone. Today, a new revolution in health science powered by big data is in process, and there is little doubt that the research accomplishments derived from this data will transform the practice of medicine. However, all stakeholders involved now have an opportunity to ensure that there is not a repeat of the ethical mistakes of the past. Risk mitigation is the responsibility of all stakeholders, from the individual

B of T Rep. 26-A-19 -- page 10 of 12

clinician and patient to the administrators and third-party data users. The privacy and security of the patient data must be protected at every point, and its use needs to be ethically conducted with the appropriate level of consent or authorization required. The HIPAA provisions, regulations enacted at the state level, and organizational policies and procedures, ensure compliance with standards developed to protect the patient. If followed appropriately, these measures can effectively protect patient data from misuse.

7

RECOMMENDATIONS

9 10

The Board of Trustees recommends that the following be adopted and the remainder of this report be filed:

11 12 13

14 15

16

 That our American Medical Association (AMA) reaffirm Policies H-315.974, "Guiding Principles, Collection and Warehousing of Electronic Medical Record Information," H-315.983, "Patient Privacy and Confidentiality," H-315.975, "Police, Payer, and Government Access to Patient Health Information," H-315.978, "Privacy and Confidentiality," and H-315.987, "Limiting Access to Medical Records." (Reaffirm HOD Policy)

17 18 19

2. That our AMA support state-based efforts to protect patient privacy including the patient's right to know whether information is being disclosed or sold and to whom and the right to opt out of the sale of their data. (New HOD Policy)

21 22

20

That our Council on Ethical and Judicial Affairs consider re-examining existing guidance
 relevant to the confidentiality of patient information in light of new practices regarding de identified patient data, including the use of exclusive de-identified data licensing agreements in
 healthcare. (Directive to Take Action)

27 28

29

4. That Policy D-315.975, "Research Handling of De-Identified Patient Information," be rescinded, as having been fulfilled by this report. (Rescind HOD Policy)

Fiscal note: Minimal – Less than \$500

REFERENCES

- 1. U.S. Department of Health and Human Services and National Institutes of Health. *Clinical Research and the HIPAA Privacy Rule*. 2004 06/22/04 [cited 2018 August 24]; Available from: https://privacyruleandresearch.nih.gov/clin_research.asp.
- 2. Rothstein, M.A., *Is Deidentification Sufficient to Protect Health Privacy in Research?* The American journal of bioethics: AJOB, 2010. 10(9): p. 3-11.
- 3. United States, *The Health Insurance Portability and Accountability Act of 1996*. 1996, U.S. Department of Labor Employee Benefits Security Administration: Washington, D.C.
- 4. U.S. Department of Health and Human Services. *Guidance Regarding Methods for De-identification of Protected Health Information in Accordance with the HIPAA Privacy Rule*. 2015 11/06/15 [cited 2018 August 24]; Available from: https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html.
- 5. U.S. Department of Health and Human Services, Summary of the HIPAA Privacy Rule. 2013.
- 6. Rothstein, M.A., *Currents in contemporary bioethics. Access to sensitive information in segmented electronic health records.* J Law Med Ethics, 2012. 40(2): p. 394-400.
- 7. Gammon, A. and D.W. Neklason, *Confidentiality & the Risk of Genetic Discrimination: What Surgeons Need to Know.* Surgical oncology clinics of North America, 2015. 24(4): p. 667-681.
- 8. U.S. Department of Health and Human Services, *HIPAA FAQs: 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.
- 9. Klein, D. Comparing the California Consumer Privacy Act (CCPA) and the EU's General Data Protection Regulation (GDPR) 2018.
- 10. State of California, California Consumer Privacy Act of 2018, in 1.81.5. 2018.
- 11. Mathews, K. and C. Bowman, *The California Consumer Privacy Act of 2018*, in *Proskauer Privacy Law Blog*, Kristen J. Mathews, Editor. 2018: California.
- 12. Orion Health, Introduction to Machine Learning in Healthcare. 2016, Orion Health.
- 13. Fatima Paruk, *How to increase adoption of machine learning in healthcare*, in *Vital Signs Blog*. 2018, Modern Healthcare.
- 14. Orion Health, *Orion Health Unveils New Predictive Intelligence Using Machine Learning to Help Save Billions in Healthcare Costs.* 2018, PRNewswire.
- 15. NCVHS Ad Hoc Workgroup for Secondary Uses of Health Data, *HIPAA Privacy Rule and Secondary Uses of Health Information*. 2007, United States Department of Health and Human Services.
- 16. U.S. Department of Health and Human Services, *Code of Federal Regulations Title 45 Public Welfare Part 46 Protection of Human Subjects*, in 45. 2009.
- 17. Federal Trade Commission, Protecting Consumer Privacy in an Era of Rapid Change. 2012.
- 18. Harvard University, *Harvard Research Data Security Policy*, Office of the Vice Provost for Research, Editor. 2014.
- 19. Federal Register, Federal Policy for the Protection of Human Subjects. Vol. 82, No. 12. January 19, 2017. Available from: https://www.govinfo.gov/content/pkg/FR-2017-01-19/pdf/2017-01058.pdf
- 20. Benitez, K. and B. Malin, *Evaluating re-identification risks with respect to the HIPAA privacy rule*. J Am Med Inform Assoc, 2010. 17(2): p. 169-77.
- 21. Sweeney, L., A. Abu, and J. Winn, *Identifying Participants in the Personal Genome Project by Name (A Re-identification Experiment)*. 2013.
- 22. Sweeney, L., *Weaving Technology and Policy Together to Maintain Confidentiality*. J Law Med Ethics, 1997. 25(2-3): p. 98-110.
- 23. Na, L., et al., Feasibility of reidentifying individuals in large national physical activity data sets from which protected health information has been removed with use of machine learning. JAMA Network Open, 2018. 1(8): p. e186040.

- 24. Gymrek, M., et al., *Identifying personal genomes by surname inference*. Science, 2013. 339(6117): p. 321-4.
- 25. El Emam, K., et al., *A Systematic Review of Re-Identification Attacks on Health Data*. PLoS ONE, 2011. 6(12): p. e28071.
- 26. Sakowitz-Klein, J., *Proposed ACO Rule Implicates HIPAA*, in *Health Reform Resource Center*. 2011, Akin Gump Strauss Hauer & Feld, LLP.
- 27. U.S. Department of Health and Human Services, *HIPAA FAQs: What is the difference between "consent" and "authorization" under the HIPAA Privacy Rule?* 2013.
- 28. 23andMe.com. *Privacy Policy*. 2018 July 17, 2018 September 17, 2018; Available from: https://www.23andme.com/about/privacy/.
- 29. Advisory Board Memorial Sloan Kettering insiders face controversy over AI startup. 2018.
- 30. Office of the National Coordinator for Health Information Technology, *Guide to Privacy and Security of Electronic Health Information*. 2015, U.S. Department of Health and Human Services.
- 31. American Academy of Family Physicians. *Data Stewardship*. 2014 [cited 2018 October 3]; Available from: https://www.aafp.org/about/policies/all/data.html.
- 32. American College of Physicians, *Policy Compendum*, D.o.G.A.a.P. Policy, Editor. 2016: Washington, DC.

REPORT OF THE COUNCIL ON CONSTITUTION AND BYLAWS

CCB Report 1-A-19

Subject: Clarification to the Bylaws: Delegate Representation, Registration and

Credentialing

Presented by: Jerome C. Cohen, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

It has come to the Council's attention that several bylaw provisions relating to representation, registration and credentialing of AMA delegates and alternate delegates are ambiguous. The Council on Constitution and Bylaws, consistent with its functions enumerated in the Bylaws, has reviewed the Bylaws and proposed changes for consideration by the House of Delegates to provisions that are inconsistent and/or lack clarity.

5 6 7

1

2

3

4

DELEGATE REPRESENTATION

8

10

11

12

13 14

15

16

17

18 19

20

21

Our AMA House of Delegates, per Article IV of the AMA Constitution, is the legislative and policymaking body of the Association. It is composed of elected representatives and others as provided in the Bylaws. The Council believes that an underlying premise of the various AMA bylaw provisions governing House of Delegates representation is that one can only represent an organization of which he/she is a member. Bylaw 2.0.1.2 speaks to the multi-dimensional role of delegates, including representation of the perspectives of the delegate's sponsoring organization, and Bylaw 2.10.3, "Lack of Credentials" alludes to the need for "proper identification as the delegate or alternate delegate selected by the respective organization." Nowhere, however, is membership in the organization being represented explicitly stated. Bylaw 2.0.1.1, "Composition and Representation," notes only that members of the House of Delegates must be active members of the AMA, but does not specify a requirement for membership in the organization being represented. Alternate delegates (who are not considered members of the House of Delegates) also are required to be AMA members, with nothing said about membership in the organization being represented.

222324

25

The Council has proposed changes to several bylaws to clarify to delegates, alternate delegates and those with responsibility for certifying them, that AMA membership and membership in the organization being represented is mandatory.

262728

DELEGATION PREREGISTRATION/CREDENTIALING

29

A delegate registration or certification process is essential in a democratic organization to ensure that only those entitled to vote may do so, and that they each vote only once. Existing AMA bylaws

32 use different terminology to identify the key individual(s) responsible for certifying the

- organization's delegates. Our AMA Bylaws for constituent associations and the national medical
- 34 specialty societies accord certification responsibility to the entity's president or secretary, while the
- bylaws for the AMA sections; the Surgeons General of the United States Army, United States
- Navy, United States Air Force, and United States Public Health Service; the Chief Medical

- 1 Director of the Department of Veterans Affairs; the National Medical Association; the American
- 2 Medical Women's Association; the American Osteopathic Association; professional interest
- 3 medical associations; and the AMA sections put the onus for certification on the president,
- 4 secretary or other authorized individual. With respect to the regional medical student delegates and
- 5 the delegates from the Resident and Fellow Section, the MSS or RFS chairs are responsible for
- 6 certifying their respective delegates and alternate delegates, although the RFS bylaws further allow
- 7 its chair to delegate the task, a provision that the MSS would welcome.

The Council has proposed amendments to several bylaw provisions to make the language more consistent across the different groups represented in our House of Delegates. While a president is recognized as the representative of any organization, certain duties/responsibilities may be delegated. In practicality, it is typically the executive director or other staff person who confirms a society's credentialed representatives to the House of Delegates.

ONSITE CREDENTIALING/REGISTRATION

Our AMA Bylaws state that "certification must occur at least 30 days prior to the Annual or Interim Meeting of the House of Delegates" and the Office of the House of Delegates Affairs works diligently with the Federation to ensure that delegate and alternate delegate certifications are received in a timely fashion. The names of the credentialed delegates and alternate delegates then become part of the Official Call, which is disseminated to all House of Delegates representatives, included in the House of Delegates Handbook, and serves as a starting point for a final list which is then published in the meeting proceedings. Nevertheless, there are always credentialed individuals who find themselves unable to attend the meeting, often at the last moment, so advance and onsite substitution of representatives occurs with some frequency. Bylaw 2.10.4 addresses the use of a "substitute delegate" when a delegate or alternate delegate is unable to attend a meeting, and Bylaw 2.10.4.1 provides for "a temporary substitute delegate" when a delegate is not able to remain in attendance for the entire meeting. Last, Bylaw 2.10.3, Lack of Credentials, permits a delegate or alternate delegate to be seated/credentialed onsite provided proper identification as the delegate or alternate delegate selected by the respective organization is established and so certified to the AMA.

 The Council has heard concerns about the onsite credentialing and recredentialing processes, particularly after the opening of the House of Delegates. At the 2018 Annual Meeting of the House of Delegates, there were some 31 onsite delegate certifications/substitutions – 12 from constituent associations, 11 from the national medical specialty societies and professional interest medical associations, 4 medical student regional delegates and 4 RFS sectional delegates. Additionally, there were 36 onsite delegate certifications/substitutions of alternate delegates (6 of which were regional medical student delegates and 9 of which were RFS sectional delegates). At the 2018 Interim Meeting, there were 35 onsite delegate certifications/substitutions – 11 from constituent associations, 15 from the national medical specialty societies and professional interest medical associations, 7 RFS sectional delegates, and 2 regional medical student delegates. Additionally, there were 23 onsite alternate delegate certifications/substitutions (of which 2 were regional medical student delegates and 5 were RFS sectional delegates).

To minimize disruption and provide clarity, the Council is proposing to modify 2.10.4. and subprovisions which speak to the formal recredentialing process and the timing of such. The Council believes that the intent of Bylaw 2.10.4.1 as written was to allow an individual <u>initially credentialed as an alternate delegate</u> (or substitute alternate delegate) to be <u>recredentialed</u> as a delegate in a delegate's absence. To provide a time frame, the Council has chosen "the first meeting of the Committee on Rules and Credentials" (Saturday morning before the opening session

of the House of Delegates) as a defined point in time by which the names and credentials of all delegates and alternate delegates can be finalized. At each House of Delegates meeting, each delegate receives a delegate badge with an appropriate ribbon, plus an additional credential that can be given to an alternate delegate should the delegate need to be out of the room at the time a vote is taken. If the delegate must leave the meeting, the delegate may formally transfer his credentials to either an alternate delegate or a (previously credentialed) substitute alternate delegate at the registration area.

PARITY

The House of Delegates has placed great emphasis on the need for parity between the constituent societies and the national medical specialty societies, and the Council, in looking at the bylaws that address registration and seating of delegates, noted an inequity. Bylaw 2.10.5 states that the current president of a constituent association may be certified as an additional alternate delegate at the discretion of each constituent association. The Council noted that there is no corresponding bylaw whereby a national medical specialty society or a professional interest medical association can achieve that. To accord the same opportunity to a national medical specialty society or a professional interest medical association to credential its president as an alternate delegate, the Council has proposed an equivalent bylaw to ensure parity and to potentially minimize vacant delegate seats for these entities.

Because of some concerns about unnecessarily swelling the size of the House, the Council looked at the registration and credentialing lists from the 2018 Annual and Interim meetings. For the A-18 meeting, there were 13 delegate vacancies from 7 national medical specialty societies or professional interest medical associations, and 101 alternate delegate vacancies from 54 societies, contrasted with only 1 constituent society with a delegate vacancy and 45 alternate delegate vacancies from 15 constituent societies. For the I-18 meeting, there were 23 delegate vacancies from 23 national specialty societies or professional interest medical association, contrasted with 5 delegate vacancies from 4 constituent societies and 62 alternate delegate vacancies from 23 constituent societies. Thus, the Council's proposed provision to extend the same courtesy to presidents of a national medical specialty society and professional interest medical association will likely not result in any significant increase in credentialed alternate delegates.

RECOMMENDATIONS

The Council on Constitution and Bylaws recommends that the following amendments to the AMA Bylaws be adopted; and that the remainder of this report be filed. Adoption requires the affirmative vote of two-thirds of the members of the House of Delegates present and voting.

2.0.1 Composition and Representation. The House of Delegates is composed of delegates selected by recognized constituent associations and specialty societies, and other delegates as provided in this bylaw.

2.0.1.1 Qualification of Members of the House of Delegates. Members of the House of Delegates must be active members of the AMA and of the entity they represent.

2.1 Constituent Associations. Each recognized constituent association granted representation in the House of Delegates is entitled to delegate representation based on the number of seats allocated to it by apportionment, and such additional delegate seats as may be

1 2		commo	ed under Bylaw 2.1.1.2. Only one constituent association from each U.S. state, onwealth, territory, or possession shall be granted representation in the House of
3 4		Delega	ites.
5		***	
6			
7		2.1.4	Certification. The president or secretary of each constituent association or the
8			president's designee shall certify to the AMA the delegates and alternate delegates
9			from their respective associations. Certification must occur at least 30 days prior to
0			the Annual or Interim Meeting of the House of Delegates.
1			
2		***	
3			
4	2.2		nal Medical Specialty Societies. The number of delegates representing national
5			al specialty societies shall equal the number of delegates representing the constituent
6			es. Each national medical specialty society granted representation in the House of
7		_	ites is entitled to delegate representation based on the number of seats allocated to it
8			ortionment, and such additional delegate seat as may be provided under Bylaw
9			The total number of delegates apportioned to national medical specialty societies
20			Bylaw 2.2.1 shall be adjusted to be equal to the total number of delegates
21			oned to constituent societies under sections 2.1.1 and 2.1.1.1.1 using methods
12		specifi	ed in AMA policy.
22 23 24	***		
25			
26		2.2.4	Certification. The president or secretary of each specialty society or the
27		2.2.7	president's designee shall certify to the AMA the delegates and alternate delegates
28			from their respective societies. Certification must occur at least 30 days prior to the
29			Annual or Interim Meeting of the House of Delegates.
80			<i>g</i>
31	***		
32			
3	2.3	Medic	al Student Regional Delegates. In addition to the delegate and alternate delegate
34		_	enting the Medical Student Section, regional Mmedical student regional delegates
35			ernate delegates shall be apportioned and elected as provided in this bylaw. Medical
86			t regional delegates and alternate delegates represent the constituent association that
37		endors	ed their candidacy pursuant to bylaw 2.3.3.
88		0.0.1	
89		2.3.1	Qualifications. Medical Sstudent Rregional delegates and alternate delegates must
0			be active medical student members of the AMA and attend medical school in the
11			medical student region from which they seek election. In addition, medical student regional delegates and alternate delegates must be members of the constituent
⊦∠ 3			association in the state wherein their educational program is located.
1 <u>1</u>			association in the state wherein their educational program is located.
2 3 4 5 6			2.3.1.1 Medical student regional alternate delegates may substitute for delegates in
16			their same region in accordance with 2.8.5 and 2.10.4.
17			
18		2.3.2	Apportionment. The total number of <u>Mm</u> edical <u>Ss</u> tudent <u>Rr</u> egional delegates and
19			alternate delegates is based on one delegate and one alternate delegate for each
0			2,000 active medical student members of the AMA, as recorded by the AMA on
51			December 31 of each year. Each <u>Mm</u> edical <u>Ss</u> tudent <u>Rregion</u> , as defined by the

1 2 3 4			Medical Student Section, is entitled to one delegate and one alternate delegate for each 2,000 active medical student members of the AMA in an educational program located within the jurisdiction of the <u>Mmedical Sstudent Rregion****</u>
5 6 7		2.3.3	Election. Medical <u>Ss</u> tudent <u>Rregional</u> delegates and alternate delegates shall be elected by the Medical Student Section in accordance with procedures adopted by the <u>Section</u> Fresh elected delegate and alternate must receive written and ergoment
8			the Section. Each elected delegate and alternate must receive written endorsement from the constituent association representing the jurisdiction within which the
9			medical student's educational program is located, in accordance with procedures
10			adopted by the Medical Student Section and approved by the Board of Trustees.
11			Delegates and alternate delegates shall be elected at the Business Meeting of the
12			Medical Student Section prior to the Interim Meeting of the House of Delegates.
13			Delegates and alternate delegates shall be seated at the Annual Meeting of the
14			House of Delegates.
15			
16		2.3.4	Certification. The Chair of the Medical Student Section Governing Council or the
17			<u>Chair's designee</u> shall certify to the AMA the delegates and alternate delegates for
18			from each Mmedical Sstudent Rregion. Certification of delegates and alternate
19			delegates must occur at least 30 days prior to the Annual Meeting of the House of
20			Delegates.
21			
22	2.4	Delega	ates from the Resident and Fellow Section. In addition to the delegate and alternate
23		delega	te representing the Resident and Fellow Section, resident and fellow physician
24		delega	tes and alternate delegates shall be apportioned and elected in a manner as provided
25		in this	bylaw.
26			
27		2.4.1	Qualifications. Delegates and alternate delegates from the Resident and Fellow
28			Section must be active members of the Resident and Fellow Section of the AMA.
29			In addition, resident and fellow physician delegates and alternate delegates must be
30			members of their endorsing constituent association, national medical specialty
31			society, federal service or professional interest medical association.
32			
33		2.4.2	Apportionment. The apportionment of delegates from the Resident and Fellow
34			Section is one delegate for each 2,000 active resident and fellow physician
35			members of the AMA, as recorded by the AMA on December 31 of each year.
36			
37		2.4.3	Election. Delegates and alternate delegates shall be elected by the Resident and
38			Fellow Section in accordance with procedures adopted by the Section. Each
39			delegate and alternate delegate must receive written endorsement from his or her a
40			constituent association, or national medical specialty society, federal service or
41			<u>professional interest medical association</u> in accordance with procedures adopted by
42			the Resident and Fellow Section and approved by the Board of Trustees.
43			
44		2.4.4	Certification. The Chair of the Resident and Fellow Section Governing Council or
45			his or her the Chair's designee shall certify to the AMA the delegates and alternate
46			delegates for the Resident and Fellow Section. Certification of delegates and
47			alternate delegates must occur at least 30 days prior to the Annual Meeting of the
48			House of Delegates.
49	ata att-		
50	***		

1 2.6 2 3 4 5 6 7	Other Delegates. Each of the following is entitled to a delegate: AMA Sections; the Surgeons General of the United States Army, United States Navy, United States Air Force, and United States Public Health Service; the Chief Medical Director of the Department of Veterans Affairs; the National Medical Association; the American Medical Women's Association; the American Osteopathic Association; and professional interest medical associations granted representation in the House of Delegates.	
8 9 0	2.6.1	Certification. The president, secretary or other authorized individual of each entity shall certify to the AMA their respective delegate and alternate delegate. Certification must occur 30 days prior to the Annual or Interim Meeting.
1 2 2.8 3 4 5		ate Delegates. Each organization represented in the House of Delegates may select mate delegate for each of its delegates entitled to be seated in the House of tes.
.6 .7	2.8.1	Qualifications. Alternate delegates must be active members of the AMA <u>and of the entity they represent.</u>
8 9 20	***	
21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39	2.8.6	Rights and Privileges. An alternate delegate may substitute for a delegate, on the floor of the House of Delegates, at the request of the delegate by complying with the procedures established by the Committee on Rules and Credentials. While briefly substituting for a delegate, the alternate delegate may speak and debate on the floor of the House, offer an amendment to a pending matter, make motions, and vote on all matters other than elections. If a delegate needs a substitute for more than half a day, then an alternate delegate must be properly recredentialed as the delegate in accordance with Bylaw 2.10.4. An alternate delegate who has been properly recredentialed as the delegate in accordance with Bylaw 2.10.4 is then considered a member of the House of Delegates, with all the rights and privileges of a delegate. Status. The alternate delegate is not a "member of the House of Delegates" as that term is used in these Bylaws. Accordingly, an alternate delegate may not introduce resolutions into the House of Delegates, nor vote in any election conducted by the House of Delegates. An alternate delegate is not eligible for nomination or election as Speaker or Vice Speaker of the House of Delegates. The An alternate delegate must immediately relinquish his or her position on the floor of the House of Delegates upon the request of the delegate for whom the alternate delegate is briefly substituting.
11 12 13	***	
2.10	Regist	ration and Seating of Delegates.
l6 l7	***	
18 19 50	2.10.2	Credentials. A delegate or alternate delegate representing a constituent association or a national medical specialty society may only be seated if there is Before being seated at any meeting of the House of Delegates, each delegate or alternate delegate shall deposit with the Committee on Rules and Credentials a certificate on

	1
	1
	2
	3
	4
	5
	6
	7
	/
	8
	9
1	0
1	1 2
1	2
1	3
1	4
1	4
I	5
1	6
1	6 7 8
1	8
1	9
っ	0
2	1
2	1
2	2
2	3
2	4
2	5
	6
2	7
2	8
2	8
2	9
3	0
<i>3</i>	1
3	2
3	2
っ っ	3 4
э 2	4
3	5
	6
3	7
	8
3	9
4	ń
4	
4	1
4	
	3
4	
4	5
4	6
4	7
4	Q
4	0
4	9
5	0

51

file submitted signed by the president, or the president's designee. secretary, or A delegate or alternate delegate representing a section, federal service or professional interest medical association may only be seated if there is a certificate on file submitted by the section chair or other authorized individual. All certificates must other authorized individual of the delegate's or alternate delegate's organization stateing that the delegate or alternate delegate has been properly selected to serve in the House of Delegates.

- **2.10.3** Lack of Credentials. A delegate or alternate delegate may be seated without the certificate defined in Bylaw 2.10.2 provided proper identification as the delegate or alternate delegate selected by the respective organization is established, and so certified to the AMA by the organization's president, the president's designee or other authorized individual.
- **2.10.4 Substitute.** When a delegate or alternate delegate is unable to attend a meeting of the House of Delegates, the appropriate authorities president, the president's designee or other authorized individual of the organization or section may appoint a substitute delegate or substitute alternate delegate prior to the first meeting of the Committee on Rules and Credentials, who on presenting proper credentials shall be eligible to serve as such delegate or alternate delegate in the House of Delegates at that meeting.
 - 2.10.4.1 **Temporary Substitute Delegate.** A delegate whose credentials have been accepted by the Committee on Rules and Credentials and whose name has been placed on the roll of the House of Delegates shall remain a delegate until final adjournment of that meeting of the House of Delegates. However, if the delegate is not able to remain in attendance, that delegate's place may be taken during the period of absence by an alternate delegate, or a substitute alternate delegate selected in accordance with Bylaw 2.10.4 if an alternate delegate is not available. The person who takes the place of the delegate must comply with the formal recredentialing procedures established by the Committee on Rules and Credentials for such purpose have a certification on file submitted by the president, the president's designee or other authorized individual of the organization or Section, and shall be known as a temporary substitute delegate. Such temporary substitute delegate shall have all of the rights and privileges of a delegate while serving as a temporary substitute delegate, including the right to vote in the House of Delegates and to vote in any election conducted by the House of Delegates. The temporary substitute delegate shall not be eligible for nomination or election as Speaker or Vice Speaker of the House of Delegates.
- **2.10.5** Constituent Association President. The current president of a constituent association may also be certified as an additional alternate delegate at the discretion of each constituent association. Certification must occur at least 30 days prior to the Annual or Interim meeting of the House of Delegates.
- 2.10.6 President of a National Medical Specialty Society or Professional Interest

 Medical Association. The current president of a national medical specialty society
 or professional interest medical association may also be certified as an additional

CCB Rep. 1-A-19 -- page 8 of 8

1	alternate delegate at the discretion of each national medical specialty society and
2	professional interest medical association with representation in the House of
3	Delegates. Certification must occur at least 30 days prior to the Annual or Interim
4	meeting of the House of Delegates.
5	
6	2.10.67 Representation. No delegate or alternate delegate may be registered credentialed
7	or seated at any meeting to represent more than one organization in the House of
8	Delegates.
9	
10	2.10.78 Medical Student Seating. Each Mmedical Sstudent Rregional delegate shall be
11	seated with the constituent association representing the jurisdiction within which
12	such delegate's educational program is located.
12 13	
14	2.10.89 Resident and Fellow Seating. Each delegate from the Resident and Fellow
15	Section shall be seated with the physician's endorsing constituent association, or
16	specialty society, federal service or professional interest medical association. In the
17	case where a delegate has been endorsed by multiple associations both a
18	constituent association and specialty society, the delegate must choose, prior to the
19	election, with which delegation the delegate wishes to be seated.

REPORT 1 OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS (1-A-19)

Competence, Self-Assessment and Self-Awareness (Reference Committee on Amendments to Constitution and Bylaws)

EXECUTIVE SUMMARY

The expectation that physicians will provide competent care is central to medicine. It undergirds professional autonomy and the privilege of self-regulation granted to medicine by society.

The ethical responsibility of competence encompasses more than knowledge and skill. It requires physicians to understand that as a practical matter in the care of actual patients, competence is fluid and dependent on context. Importantly, the ethical responsibility of competence requires that physicians at all stages of their professional lives be able to recognize when they are and when they are not able to provide appropriate care for the patient in front of them or the patients in their practice as a whole.

Self-aware physicians discern when they are no longer comfortable handling a particular type of case and know when they need to obtain more information or need additional resources to supplement their own skills. They recognize when they should ask themselves whether they should postpone care, arrange to have a colleague provide care, or otherwise find ways to protect the patient's well-being.

To fulfill their ethical responsibility of competence, physicians at all stages in their professional lives should cultivate and exercise skills of self-awareness and active self-observation; take advantage of tools for self-assessment that are appropriate to their practice settings and patient populations; and be attentive to environmental and other factors that may compromise their ability to bring their best skills to the care of individual patients. As a profession, medicine should provide meaningful opportunity for physicians to hone their ability to be self-reflective.

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 1-A-19

Subject: Competence, Self-Assessment and Self-Awareness

Presented by: James E. Sabin, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William C. Reha, MD, MBA, Chair)

The expectation that physicians will provide competent care is central to medicine. This expectation shaped the founding mission of the American Medical Association (AMA) and runs throughout the AMA *Code of Medical Ethics* [1-4]. It undergirds professional autonomy and the privilege of self-regulation granted to medicine by society [5]. The profession promises that practitioners will have the knowledge, skills, and characteristics to practice safely and that the profession as a whole and its individual members will hold themselves accountable to identify and address lapses [6-9].

1 2

Yet despite the centrality of competence to professionalism, the *Code* has not hitherto examined what the commitment to competence means as an ethical responsibility for individual physicians in day-to-day practice. This report by the Council on Ethical and Judicial Affairs (CEJA) explores this topic to develop ethics guidance for physicians.

DEFINING COMPETENCE

A caveat is in order. Various bodies in medicine undertake point-in-time, cross-sectional assessments of physicians' technical knowledge and skills. However, this report is not concerned with matters of technical proficiency assessed by medical schools and residency programs, specialty boards (for purposes of certification), or hospital and other health care organizations (e.g., for privileging and credentialing). Such matters lie outside the Council's purview.

The ethical responsibility of competence encompasses more than knowledge and skill. It requires physicians to understand that as a practical matter in the care of actual patients, competence is fluid and dependent on context. Importantly, the ethical responsibility of competence requires that physicians at all stages of their professional lives be able to recognize when they are and when they are not able to provide appropriate care for the patient in front of them or the patients in their practice as a whole. For purposes of this analysis, competence is understood as "the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and the community being served" and as "developmental, impermanent, and context dependent" [10].

Moreover, the Council is keenly aware that technical proficiency evolves over time—what is expected of physicians just entering practice is not exactly the same as what is expected of mid-

^{*} Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

career physicians or physicians who are changing or re-entering practice or transitioning out of active practice to other roles. Each phase of a medical career, from medical school through retirement, carries its own implications for what a physician should know and be able to do to practice safely and to maintain effective relationships with patients and with colleagues.

The concept that informs this report differs as well from the narrower definition of competence as the knowledge and skills an individual has to do a job. Rather, this report explores a broader notion of competence that encompasses deeper aspects of wisdom, judgment and practice that enable physicians to assure patients, the public, and the profession that they provide safe, high quality care moment to moment over the course of a professional lifetime.

FROM SELF-ASSESSMENT TO "INFORMED" SELF-ASSESSMENT

 Health care institutions and the medical profession as a whole take responsibility to regulate physicians through credentialing and privileging, routinely testing knowledge (maintenance of certification, requirements for continuing education, etc.) and, when needed, taking disciplinary action against physicians who fail to meet expectations for competent, professional practice. However, the better part of the responsibility to maintain competence rests with physicians' "individual capacity, as clinicians, to self-assess [their] strengths, deficiencies, and learning needs to maintain a level of competence commensurate with [their] clinical roles" [11].

 Self-assessment has thus become "integral to many appraisal systems and has been espoused as an important aspect of personal professional behavior by several regulatory bodies and those developing learning outcomes for students" [12]. Undergraduate and graduate medical education programs regularly use self-assessment along with third-party evaluations to ensure that trainees are acquiring the knowledge and skills necessary for competent practice [5,10,13-16].

 Yet how accurately physicians assess their own performance is open to question. Research to date suggests that there is poor correlation between how physicians rate themselves and how others rate them [5,12,13]. Various studies among health professionals have concluded that clinicians and trainees tend to assess their peers' performance more accurately than they do their own; several have found that poor performers (e.g., those in the bottom quartile) tend to over-estimate their abilities while high performers (e.g., those in the top quartile), tend to under-estimate themselves [5,12,17].

The available findings suggest that self-assessment involves an interplay of factors that can be complicated by lack of insight or of metacognitive skill, that is, ability to be self-observant in the moment. Similarly, personal characteristics (e.g., gender, ethnicity, or cultural background) and the impact of external factors (e.g., the purpose of self-assessment or whether it is designed to assess practical skills or theoretical knowledge) can all affect self-assessment [12,18]. The published literature also indicates that interventions intended to enhance self-assessment may seek different goals—improving the accuracy of self-assessors' perceptions of their learning needs, promoting appropriate change in learning activities, or improving clinical practice or patient outcomes [12].

Self-assessment tools alone are not sufficient measures of physicians' ability to provide safe, high quality care. Feedback from third parties is essential—or as one researcher has observed, "The road to self-knowledge may run through other people" [19]. However, physicians are often wary of assessment. They have indicated that while they want feedback, they are not sure how to use information that is not congruent with their self-appraisals [20]. Physicians can be hesitant to seek feedback for fear of looking incompetent or exposing possible deficiencies or out of concern that soliciting feedback could adversely affect their relationships with those whom they approach [20].

They may also question the accuracy and credibility of the assessment process and the data it generates [21].

To be effective, feedback must be valued both by those being assessed and by those offering assessment [14]. When there is tension between the stated goals of assessment and the implicit culture of the health care organization or institution, assessment programs can too readily devolve into an activity undertaken primarily to satisfy administrators that rarely improves patient care [20]. Feedback mechanisms should be appropriate to the skills being assessed—multi-source reviews ("360° reviews"), for example, are generally better suited to providing feedback on communication and interpersonal skills than on technical knowledge or skills—and easy for evaluators to understand and use [14]. High quality feedback will come from multiple sources; be specific and focus on key elements of the ability being assessed; address behaviors rather than personality or personal characteristics; and "provide both positive comments to reinforce good behavior and constructive comments with action items to address deficiencies" [22]. Beyond such formal mechanisms, physicians should welcome and seek out informal input from colleagues. They should be willing to offer timely comments to colleagues as well.

One study among physicians and physicians in training found that participants used a dynamic, multidimensional process to assess their own abilities. Under this process of what researchers identified as "informed self-assessment," participants interpreted and responded to multiple types of information, such as cognitive and affective data, from both formal and informal sources [23]. Participants described "critically reflecting 'in action,' that is, during an activity or throughout the day:"

I think we do a lot of it without thinking of it as reflection. We do it every day when we look at a patient's chart. You look back and see the last visit, "What did I do, or should I have done something different?" I mean that's reflection, but yet I wouldn't have thought of that as self-assessment or self-reflection, but we do it dozens of times a day [23].

EXPERTISE & EXPERT JUDGMENT

 On this broad understanding of competence, physicians' thought processes are as important as their knowledge base or technical skills. Thus, understanding competence requires understanding something of the nature of expertise and processes of expert reasoning, themselves topics of ongoing exploration [24,25,26,27]. Prevailing theory distinguishes "fast" from "slow" thinking; that is, reflexive, intuitive processes that require minimal cognitive resources versus deliberate, analytical processes that require more conscious effort [26]. Some scholars take expertise to involve "fast" processes, and specifically decision making that involves automatic, nonanalytic resources acquired through experience [24]. Others argue that expertise consists in using "slow," effortful, analytic processes to address problems [24]. A more integrative view argues that expertise resides in being able to transition between intuitive and analytical processes as circumstances require. On this account, experts use automatic resources to free up cognitive capacity so that they maintain awareness of the environment ("situational awareness") and can determine when to shift to effortful processes [24].

Expert judgment is the ability "to respond effectively in the moment to the limits of [one's] automatic resources and to transition appropriately to a greater reliance on effortful processes when needed" [24], a practice described as "slowing down." Knowing when to slow down and be reflective has been demonstrated to improve diagnostic accuracy and other outcomes [26]. To respond to the unexpected events that often arise in a clinical situation, the physician must "vigilantly monitor relevant environmental cues" and use these as signals to slow down, to

transition into a more effortful state [25]. This can happen, for example, when a surgeon confronts an unexpected tumor or anatomical anomaly during a procedure. "Slowing down when you should" serves as a critical marker for intraoperative surgical judgment [24].

1 2

INFLUENCES ON CLINICAL REASONING

Clinical reasoning is a complex endeavor. Physicians' capabilities develop through education, training, and experiences that provide tools with which to shape their clinical reasoning. Every physician arrives at a diagnosis and treatment plan for an individual in ways that may align with or differ from the analytical and investigative processes of their colleagues in innumerable ways. When something goes wrong in the clinic, it can be difficult to discern why. Nonetheless, all physicians are open to certain common pitfalls in reasoning, including relying unduly on heuristics and habits of perception, and succumbing to overconfidence.

Heuristics

Physicians often use various heuristics—i.e., cognitive short cuts—to aid decision making. While heuristics can be useful tools to help physicians identify and categorize relevant information, these time-saving devices can also derail decision making. For example, a physician may mistakenly assume that "something that seems similar to other things in a certain category is itself a member of that category" (the representative heuristic) [28], and fail to diagnose a serious health problem. Imagine a case in which a patient presents with symptoms of a possible heart attack or a stroke that the physician proceeds to discount as stress or intoxication once the physician learns that the patient is going through a divorce or smells alcohol on the patient's breath. Or a physician may miscalculate the likelihood of a disease or injury occurring by placing too much weight "on examples of things that come to mind easily, . . . because they are easily remembered or recently encountered" (the availability heuristic) [28]. For example, amidst heavy media coverage of an outbreak of highly infectious disease thousands of miles away in a remote part of the world, a physician seeing a patient with symptoms of what is actually a more commonplace illness may misdiagnose (or over diagnose) the exotic condition because that is what is top of mind.

 Clinical reasoning can be derailed by other common cognitive missteps as well. These can include misperceiving a coincidental relationship as a causal relationship (illusory bias), or the tendency to remember information transferred at the beginning (or end) of an exchange but not information transferred in the middle (primary or recency bias) [28,29,30].

Habits of Perception

Like every other person, physicians can also find themselves prone to explicit (conscious) or implicit (unconscious) habits of perception or biases. Physicians may allow unquestioned assumptions based on a patient's race or ethnicity, gender, socioeconomic status, or health behavior, among other features, to shape how they perceive the patient and how they engage with, evaluate and treat the individual. Basing one's interactions with a patient on pre-existing expectations or stereotypes demeans the patient, undermines the patient's relationship with the physician and the health care system, and can result in significant health disparities across entire communities [31]. This is of particular concern for patients who are members of minority and historically disadvantaged populations [31]. Physicians may fall victim to the tendency to seek out information that confirms established expectations or dismiss contradicting information that does not fit into predetermined beliefs (confirmatory bias) [28]. These often inadvertent thought processes can result in a physician pursuing an incorrect line of questioning or testing that then leads to a misdiagnosis or the wrong treatment.

No matter how well a patient may seem to fit a stereotype, it is imperative that the physician look beyond categories and assumptions to investigate openly the health issues experienced by the patient. Although all human beings exhibit both conscious and unconscious habits of perception, physicians must remain vigilant in not allowing preconceived or unexamined assumptions to influence their medical practice.

Overconfidence

Finally, another obstacle to strong clinical reasoning that physicians may encounter is overconfidence. Despite their extensive training, physicians, like all people, are poor at identifying the gaps in their knowledge [28,30]. Physicians may consider their skills to be excellent, when, in fact, their peers have identified areas for improvement [30]. Overconfidence in one's abilities can lead to suboptimal care for a patient, be it through mismanaging resources, failing to consider the advice of others, or not acknowledging one's limits [28,30].

To avoid falling into such traps, physicians must recognize that many factors can and will influence their clinical decisions [28]. They need to be aware of the information they do and do not have and they need to acknowledge that many factors can and will influence their judgment. They should keep in mind the likelihood of diseases and conditions and take the time to distinguish information that is truly essential to sound clinical judgment from the wealth of possibly relevant information available about a patient. They should consider reasons their decisions may be wrong and seek alternatives, as well as seek to disprove rather than confirm their hypotheses [28]. And they should be sensitive to the ways in which assumptions may color their reasoning and not allow expectations to govern their interactions with patients.

Shortcomings can be an opportunity for growth in medicine, as in any other field. By becoming aware of areas in which their skills are not at their strongest and seeking additional education or consulting with colleagues, physicians can enhance their practice and best serve their patients.

Physicians' ability to practice safely can be affected by their own health, of course. The *Code of Medical Ethics* addresses such situations in guidance on physicians' health and wellness (<u>E-9.3.1</u>) and their responsibilities to impaired colleagues (<u>E-9.3.2</u>).

FROM INFORMED SELF-ASSESSMENT TO SELF-AWARENESS

Recognizing that many factors affect clinical reasoning and that self-assessment as traditionally conceived has significant shortcomings, several scholars have argued that a different understanding of self-assessment is needed, along with a different conceptualization of its role in a self-regulating profession [32]. Self-assessment, it is suggested, is a mechanism for identifying both one's weaknesses and one's strengths. One should be aware of one's weaknesses in order to self-limit practice in areas in which one has limited competence, to help set appropriate learning goals, and to identify areas that "should be accepted as forever outside one's scope of competent practice" [32]. Knowing one's strengths, meanwhile, allows a physician both to "act with appropriate confidence" and to "set appropriately challenging learning goals" that push the boundaries of the physician's knowledge [32].

If self-assessment is to fulfill these functions, physicians need to reflect on past performance to evaluate not only their general abilities but also specific completed performances. At the same time, they must use self-assessment predictively to assess how likely they are to be able to manage new challenges and new situations. More important, physicians should understand self-assessment as an ongoing process of monitoring tasks during performance [3]. The ability to monitor oneself in

the moment is critical to physicians' ethical responsibility to practice safely, at the top of their expertise but not beyond it.

Expert practitioners rely on pattern recognition and other automatic resources to be able to think and act intuitively. As noted above, an important component of expert judgment is transitioning effectively from automatic modes of thinking to more effortful modes as the situation requires. Self-awareness, in the form of attentive self-observation (metacognitive monitoring), alerts physicians when they need to direct additional cognitive resources to the immediate task. For example, among surgeons, knowing when to "slow down" during a procedure is critical to competent professional performance, whether that means actually stopping the procedure, withdrawing attention from the surrounding environment to focus more intently on the task at hand, or removing distractions from the operating environment [25].

 Physicians should also be sensitive to the ways that interruptions and distractions, which are common in health care settings, can affect competence in the moment [34,35], by disrupting memory processes, particularly the "prospective memory"—i.e., "a memory performance in which a person must recall an intention or plan in the future without an agent telling them to do so"—important for resuming interrupted tasks [35,36]. Systems-level interventions have been shown to help reduce the number or type of interruptions and distractions and mitigate their impact on medical errors [37].

A key aspect of competence is demonstrating situation-specific awareness in the moment of being at the boundaries of one's knowledge and responding accordingly [33]. Slowing down, looking things up, consulting a colleague, or deferring from taking on a case can all be appropriate responses when physicians' self-awareness tells them they are at the limits of their abilities. The capacity for ongoing, attentive self-observation, for "mindful" practice, is an essential marker of competence broadly understood:

Safe practice in a health professional's day-to-day performance requires an awareness of when one lacks the specific knowledge or skill to make a good decision regarding a particular patient This decision making in context is importantly different from being able to accurately rate one's own strengths and weaknesses in an acontextual manner. . . . Safe practice requires that self-assessment be conceptualized as repeatedly enacted, situationally relevant assessments of self-efficacy and ongoing 'reflection-in-practice,' addressing emergent problems and continuously monitoring one's ability to effectively solve the current problem [32].

Self-aware physicians discern when they are no longer comfortable handling a particular type of case and know when they need to obtain more information or need additional resources to supplement their own skills [32]. Self-aware physicians are also alert to how external stressors—the death of a loved one or other family crisis, or the reorganization of their practice, for example—may be affecting their ability to provide care appropriately at a given time. They recognize when they should ask themselves whether they should postpone care, arrange to have a colleague provide care, or otherwise find ways to protect the patient's well-being.

MAINTAINING COMPETENCE ACROSS A PRACTICE LIFETIME

For physicians, the ideal is not simply to be "good" practitioners, but to excel throughout their professional careers. This ideal holds not just over the course of a sustained clinical practice, but equally when physicians re-enter practice after a hiatus, transition from active patient care to roles as educators or administrators, or take on other functions in health care. Self-assessment and self-awareness are central to achieving that goal.

A variety of strategies are available to physicians to support effective self-assessment and help physicians cultivate the kind of self-awareness that enables them to "know when to slow down" in day-to-day practice. One such strategy might be to create a portfolio of materials for reflection in the form of written descriptions, audio or video recording, or photos of encounters with patients that can provide evidence of learning, achievement and accomplishment [16] or of opportunities to improve practice. A strength of portfolios as a tool for assessing one's practice is that, unlike standardized examinations, they are drawn from one's actual work and require self-reflection [15].

As noted above, to be effective, self-assessment must be joined with input from others. Well-designed multi-source feedback can be useful in this regard, particularly for providing information about interpersonal behaviors [14]. Research has shown that a four-domain tool with a simple response that elicits feedback about how well one maintains trust and professional relationships with patients, one's communication and teamwork skills, and accessibility offers a valid, reliable tool that can have practical value in helping to correct poor behavior and, just as important, consolidate good behavior [14]. Informal arrangements among colleagues to provide thoughtful feedback will not have the rigor of a validated tool but can accomplish similar ends.

 Reflective practice, that is, the habit of using critical reflection to learn from experience, is essential to developing and maintaining competence across a physician's practice lifetime [38]. It enables physicians to "integrate personal beliefs, attitudes, and values in the context of professional culture," and to bridge new and existing knowledge. Studies suggest that reflective thinking can be assessed, and that it can be developed, but also that the habit can be lost over time with increasing years in practice [38].

"Mindful practice," that is, being fully present in everyday experience and aware of one's own mental processes (including those that cloud decision making) [39], sustains the attitudes and skills that are central to self-awareness. Medical training, with its fatigue, dogmatism, and emphasis on behavior over consciousness, erects barriers to mindful practice, while an individual's unexamined negative emotions, failure of imagination, and literal-mindedness can do likewise. Mindfulness can be self-taught, but for most it is most effectively learned in relationship with a mentor or guide. Nonetheless, despite challenges, there are myriad ways physicians can cultivate mindfulness. Meditation, which may come first to mind, is one, but so is keeping a journal, reviewing videos of encounters with patients, or seeking insight from critical incident reports [39].

"Exemplary physicians," one scholar notes, "seem to have a capacity for self-critical reflection that pervades all aspects of practice, including being present with the patient, solving problems, eliciting and transmitting information, making evidence-based decisions, performing technical skills, and defining their own values" [39].

RECOMMENDATION

The Council on Ethical and Judicial Affairs recommends that the following be adopted and the remainder of this report be filed:

 The expectation that physicians will provide competent care is central to medicine. It undergirds professional autonomy and the privilege of self-regulation granted by society. To this end, medical schools, residency and fellowship programs, specialty boards, and other health care organizations regularly assess physicians' technical knowledge and skills. However, as an ethical responsibility competence encompasses more than medical knowledge and skill. It requires physicians to understand that as a practical matter in the care of actual patients, competence is fluid and dependent on context. Each phase of a medical career, from

CEJA Rep. 1-A-19 -- page 8 of 10

1	medical school through retirement, carries its own implications for what a physician should
2	know and be able to do to practice safely and to maintain effective relationships with patients
3	and with colleagues. Physicians at all stages of their professional lives need to be able to
4	recognize when they are and when they are not able to provide appropriate care for the patient
5	in front of them or the patients in their practice as a whole.
6	r
7	To fulfill the ethical responsibility of competence, individual physicians and physicians in
8	training should strive to:
9	6
10	(a) Cultivate continuous self-awareness and self-observation.
11	
12	(b) Recognize that different points of transition in professional life can make different
13	demands on competence.
14	
15	(c) Take advantage of well-designed tools for self-assessment appropriate to their practice
16	settings and patient populations.
17	
18	(d) Seek feedback from peers and others.
19	
20	(e) Be attentive to environmental and other factors that may compromise their ability to
21	bring appropriate skills to the care of individual patients and act in the patient's best
22	interest.
23	
24	(f) Intervene in a timely and appropriate manner when a colleague's ability to practice
25	safely is compromised by impairment, in keeping with ethics guidance on physicians'
26	responsibilities to impaired colleagues.
27	
28	Medicine as a profession should continue to refine mechanisms for assessing knowledge and
29	skill and should develop meaningful opportunities for physicians and physicians in training to
30	hone their ability to be self-reflective and attentive in the moment.

(New HOD/CEJA Policy)

Fiscal Note: Less than \$500.

REFERENCES

- 1. American Medical Association Code of Medical Ethics. Principle I. Available at http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page. Accessed August 20, 2016.
- 2. American Medical Association Code of Medical Ethics. Opinion 11.2.1, Professionalism in health care systems. Available at http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page. Accessed August 20, 2016.
- 3. American Medical Association Code of Medical Ethics. Opinion 1.2.3, Consultation, referral and second opinions. Available at http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page. Accessed August 20, 2016.
- 4. American Medical Association Code of Medical Ethics. Opinion 1.1.6, Quality. Available at http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page. Accessed August 20, 2016.
- 5. Gordon MJ. A review of the validity and accuracy of self-assessments in health professions training. *Acad Med.* 1991;66:762–769.
- 6. American Medical Association Code of Medical Ethics. Principle II. Available at http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page. Accessed August 20, 2016.
- 7. American Medical Association Code of Medical Ethics. Opinion 9.4.2, Reporting incompetent or unethical behavior by colleagues. Available at http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page. Accessed August 20, 2016.
- 8. American Medical Association Code of Medical Ethics. Opinion 9.4.3, Discipline and medicine. Available at http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page. Accessed August 20, 2016.
- 9. American Medical Association Code of Medical Ethics. Opinion 8.6, Promoting patient safety. Available at http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page. Accessed August 20, 2016.
- 10. Epstein RM, Hundert EM. Defining and assessing professional competence. *JAMA*. 2002;287(2):226–235.
- 11. Epstein RM, Siegel DJ, Silberman J. Self-monitoring in clinical practice: a challenge for medical educators. *J Contin Educ Health Professions*. 2008;28(1):5–13.
- 12. Colthart I, Bagnall G, Evans A, et al. The effectiveness of self-assessment on the identification of learner needs, learner activity, and impact on clinical practice: BEME Guide no. 10. *Medical Teacher*. 2008;30:124–145.
- 13. DA, Mazmanian PE, Fordis M, et al. Accuracy of physician self-assessment compared with observed measures of competence: a systematic review. *JAMA*. 2006;296:1094–1102.
- 14. Whitehouse A, Hassell A, Bullock A, et al. 360 degree assessment (multisource feedback) of UK trainee doctors: filed testing of team assessment behaviors (TAB). *Medical Teacher*. 2007;29:171–178.
- 15. O'Sullivan P, Greene C. Portfolios: possibilities for addressing emergency medicine resident competencies. *Acad Emerg Med.* 2002;9(11):1305–1309.
- 16. Leigh IW, Smith IL, Bebeau M, et al. Competency assessment models. *Professional Psychology: Research and Practice*. 2007;38(5):463–473.
- 17. Lipsett PA, Harris I, Downing S. Resident self-other assessor agreement: influence of assessor, competency, and performance level. *Arch Surg.* 2011;146(8):901–906.
- 18. Svirko E, Lambert T, Goldacre MJ. Gender, ethnicity and graduate status, and junior doctors' self-reported preparedness for clinical practice: national questionnaire surveys. J *Royal Society Med.* 2014;107(2):66–74.
- 19. Dunning D. Strangers to ourselves? *The Psychologist*. 2006;19(10):600–603.

- 20. Mann K, van der Vleuten C, Eva K, et al. Tensions in informed self-assessment: how the desire for feedback and reticence to collect and use it can conflict. *Acad Med.* 2011;86(9):1120–1127.
- 21. Sargeant J, Mann K, Ferrier S. Exploring family physicians' reactions to multisource feedback: perceptions of credibility and usefulness. *Medical Education*. 2005;39:497–504.
- 22. Jackson JL, Kay C, Jackson WC, Frank M. The quality of written feedback by attendings of internal medicine residents. *J Gen Intern Med*. 2015;30(7):973–978.
- 23. Sargeant J, Amson H, Chesluk B, et al. The processes and dimensions of informed self-assessment: a conceptual model. *Acad Med.* 2010;85:1212–1220.
- 24. Moulton CE, Regehr G, Mylopoulous M, MacRae HM. Slowing down when you should: a new model of expert judgment. *Acad Med.* 2007;82(10 Suppl):S109–S116.
- 25. Moulton C, Regehr G, Lingard L, et al. Slowing down to stay out of trouble in the operating room: remaining attentive in automaticity. *Acad Med.* 2010;85(10):1571–1577.
- 26. Croskerry P. Achieving quality in clinical decision making: cognitive strategies and detection of bias. *Acad Emerg Med.* 2002;9(11):1184–1204.
- 27. Sklar DP. How do we think? can we learn to think? Acad Med. 2014;89:191–193.
- 28. Klein JG. Five pitfalls in decisions about diagnosis and prescribing. BMJ 2005;330:781–784.
- 29. Croskerry P, Petrie DA, Reilly B, Tait G. Deciding about fast and slow decisions. *Acad Med.* 2014;89:197–200.
- 30. Kadar N. Peer review of medical practices: missed opportunities to learn. *AJOG*. 2014; Dec:596–601.
- 31. Cooper LA, Roter DL, Carson KA, et al. The association of clinicians' implicit attitudes about race with medical visit communication and patient ratings of interpersonal care. *Am J Public Health*. 2012;102:979–987.
- 32. Eva KW, Regehr G. Self-assessment in the health professions: a reformulation and research agenda. *Acad Med.* 2005;80(10 Suppl):S46–S54.
- 33. Eva KW, Regehr G. Knowing when to look it up: a new conception of self-assessment ability. *Acad Med.* 2007;82(10 Suppl): 581–584.
- 34. Rivera AJ, Karsh B-T. Interruptions and distractions in healthcare: review and reappraisal. *Qual Saf Health Care*. 2010;19(4):304–312.
- 35. Grundgeiger T, Sanderson P. Interruptions in health care: theoretical views. *Intl J Med Informatics*. 2009;78:293–307.
- 36. Monsell S. Task switching. TRENDS in Cog Sciences. 2003;7(3).
- 37. Relihan E, O'Brien V, O'Hara S, et al. The impact of a set of interventions to reduce interruptions and istractions to nurses during medication administration. *Qual Saf Health Care*. 2010; May 28.
- 38. Mann K, Gordon J, MacLeod A. Reflection and reflective practice in health professions education: a systematic review. *Adv in Health Sci Educ.* 2009;14:595–621.
- 39. Epstein RM. Mindful practice. JAMA. 1999;282(9::833-839.

REPORT 2 OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS (2-A-19)

Physician-Assisted Suicide (Resolution 15-A-16 and Resolution 14-A-17) (Reference Committee on Amendments to Constitution and Bylaws)

EXECUTIVE SUMMARY

The House of Delegates asked the Council on Ethical and Judicial Affairs (CEJA) to "study the issue of aid in dying with consideration of data collected from the states that currently authorize aid-in-dying, and input from some of the physicians who have provided medical aid-in-dying to qualified patients. CEJA was further asked to consider the need to distinguish between "physician-assisted suicide" and "aid in dying."

In response to these requests, CEJA carried out an extensive review of relevant philosophical and empirical literature. Its deliberations have further been informed by an educational session at the 2016 Interim Meeting and consultations with stakeholders at the 2017 Annual and Interim meetings, as well as extensive correspondence from stakeholders within the medical community and the public at large. In addition, the council heard passionate testimony from both opponents and supporters of physician participation in assisted suicide at the 2018 Annual and Interim meetings.

Reflecting on this input, CEJA recognized that thoughtful, morally admirable individuals hold diverging, yet equally deeply held and well-considered perspectives about physician-assisted suicide. Importantly, the council found that despite deep differences, supporters and opponents share a fundamental commitment to values of care, compassion, respect, and dignity; they diverge in drawing different moral conclusions from those underlying values in equally good faith.

CEJA interprets existing guidance in the AMA *Code of Medical Ethics* as encompassing the irreducible moral tension at stake for physicians with respect to participating in assisted suicide.

Because Opinion E-5.7 powerfully expresses the perspective of those who oppose physician-assisted suicide and Opinion E-1.1.7 articulates the thoughtful moral basis for those who support assisted suicide, CEJA recommends that the *Code of Medical Ethics* not be amended.

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 2-A-19

Subject: Physician-Assisted Suicide

(Resolution 15-A-16 and Resolution 14-A-17)

Presented by: James E. Sabin, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William C. Reha, MD, MBA, Chair)

At the 2016 Annual Meeting, the House of Delegates referred Resolution 15-A-16, "Study Aid-in-Dying as End-of-Life Option," presented by the Oregon Delegation, which asked:

That our American Medical Association (AMA) and its Council on Judicial and Ethical Affairs (CEJA), study the issue of medical aid-in-dying with consideration of (1) data collected from the states that currently authorize aid-in-dying, and (2) input from some of the physicians who have provided medical aid-in-dying to qualified patients, and report back to the HOD at the 2017 Annual Meeting with recommendation regarding the AMA taking a neutral stance on physician "aid-in-dying."

At the following Annual Meeting in June 2017, the House of Delegates similarly referred Resolution 14-A-17, "The Need to Distinguish between 'Physician-Assisted Suicide' and 'Aid in Dying'" (presented by M. Zuhdi Jasser, MD), which asked that our AMA:

 (1) as a matter of organizational policy, when referring to what it currently defines as 'Physician Assisted Suicide' avoid any replacement with the phrase 'Aid in Dying' when describing what has long been understood by the AMA to specifically be 'Physician Assisted Suicide'; (2) develop definitions and a clear distinction between what is meant when the AMA uses the phrase 'Physician Assisted Suicide' and the phrase 'Aid in Dying'; and (3) fully utilize these definitions and distinctions in organizational policy, discussions, and position statements regarding both 'Physician Assisted Suicide' and 'Aid in Dying.'

This report by the Council on Ethical and Judicial Affairs addresses the concerns expressed in Resolutions 15-A-16 and 14-A-17. In carrying out its review of issues in this area, CEJA reviewed the philosophical and empirical literature, sought input from the House of Delegates through an I-16 educational program on physician-assisted suicide, an informal "open house" at A-17, and its I-17 Open Forum. The council wishes to express its sincere appreciation for participants' contributions during these sessions and for additional written communications received from multiple stakeholders, which have enhanced its deliberations.

The council observes that the ethical arguments advanced today supporting and opposing "physician-assisted suicide" or "aid in dying" are fundamentally unchanged from those examined

^{*} Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

in CEJA's 1991 report on this topic [1]. The present report does not rehearse these arguments again as such. Rather, it considers the implications of the legalization of assisted suicide in the United States since the adoption of Opinion E-5.7, "Physician-Assisted Suicide," in 1994.

1 2

"ASSISTED SUICIDE," "AID IN DYING," OR "DEATH WITH DIGNITY"?

Not surprisingly, the terms stakeholders use to refer the practice of physicians prescribing lethal medication to be self-administered by patients in many ways reflect the different ethical perspectives that inform ongoing societal debate. Proponents of physician participation often use language that casts the practice in a positive light. "Death with dignity" foregrounds patients' values and goals, while "aid in dying" invokes physicians' commitment to succor and support. Such connotations are visible in the titles of relevant legislation in states that have legalized the practice: "Death with Dignity" (Oregon, Washington, District of Columbia), "Patient Choice and Control at the End of Life" (Vermont), "End of Life Options" (California, Colorado), "Our Care Our Choice Act" (Hawaii), and in Canada's "Medical Aid in Dying."

Correspondingly, those who oppose physician provision of lethal medications refer to the practice as "physician-assisted suicide," with its negative connotations regarding patients' psychological state and its suggestion that physicians are complicit in something that, in other contexts, they would seek to prevent. The language of dignity and aid, critics contend, are euphemisms [2]; their use obscures or sanitizes the activity. In their view such language characterizes physicians' role in a way that risks construing an act that is ethically unacceptable as good medical practice [3]. Still others, meanwhile, argue that the choice by terminally ill patients to take action to end their own lives with the assistance of their physician is distinct from what is traditionally understood as "suicide" [4].

 The council recognizes that choosing one term of art over others can carry multiple, and not always intended messages. However, in the absence of a perfect option, CEJA believes ethical deliberation and debate is best served by using plainly descriptive language. In the council's view, despite its negative connotations [5], the term "physician assisted suicide" describes the practice with the greatest precision. Most importantly, it clearly distinguishes the practice from euthanasia [1]. The terms "aid in dying" or "death with dignity" could be used to describe either euthanasia or palliative/hospice care at the end of life and this degree of ambiguity is unacceptable for providing ethical guidance.

COMMON GROUND

 Beneath the seemingly incommensurate perspectives that feature prominently in public and professional debate about writing a prescription to provide patients with the means to end life if they so choose, CEJA perceives a deeply and broadly shared vision of what matters at the end of life. A vision that is characterized by hope for a death that preserves dignity, a sense of the sacredness of ministering to a patient at the end of life, recognition of the relief of suffering as the deepest aim of medicine, and fully voluntary participation on the part of both patient and physician in decisions about how to approach the end of life.

Differences lie in the forms these deep commitments take in concrete decisions and actions. CEJA believes that thoughtful, morally admirable individuals hold diverging, yet equally deeply held, and well-considered perspectives about physician-assisted suicide that govern how these shared commitments are ultimately expressed. For one patient, dying "with dignity" may mean accepting the end of life however it comes as gracefully as one can; for another, it may mean being able to exercise some measure of control over the circumstances in which death occurs. For some

physicians, the sacredness of ministering to a terminally ill or dying patient and the duty not to abandon the patient preclude the possibility of supporting patients in hastening their death. For others, not to provide a prescription for lethal medication in response to a patient's sincere request violates that same commitment and duty. Both groups of physicians base their view of ethical practice on the guidance of Principle I of the AMA *Principles of Medical Ethics*: "A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights."

So too, how physicians understand and act on the goals of relieving suffering, respecting autonomy, and maintaining dignity at the end of life is directed by identity-conferring beliefs and values that may not be commensurate. Where one physician understands providing the means to hasten death to be an abrogation of the physician's fundamental role as healer that forecloses any possibility of offering care that respects dignity, another in equally good faith understands supporting a patient's request for aid in hastening a foreseen death to be an expression of care and compassion.

IRREDUCIBLE DIFFERENCES IN MORAL PERSPECTIVES ON PHYSICIAN-ASSISTED SUICIDE

How to respond when coherent, consistent, and deeply held beliefs yield irreducibly different judgments about what is an ethically permissible course of action is profoundly challenging. With respect to physician-assisted suicide, some professional organizations—for example, the American Academy of Hospice and Palliative Medicine [6]—have adopted a position of "studied neutrality." Positions of studied neutrality neither endorse nor oppose the contested practice, but instead are intended to respect that there are irreducible differences among the deeply held beliefs and values that inform public and professional perspectives [6,7], and to leave space open for ongoing discussion. Nonetheless, as a policy position, studied neutrality has been criticized as neither neutral or appropriate for organized medicine [8], and as being open to unintended consequences, including stifling the very debate it purports to encourage or being read as little more than acquiescence with the contested practice [9].

CEJA approaches the condition of irreducible difference from a different direction. In its 2014 report on exercise of conscience, the Council noted that "health care professionals may hold very different core beliefs and thus reach very different decisions based on those core beliefs, yet equally act according to the dictates of conscience. For example, a physician who chooses to provide abortions on the basis of a deeply held belief in protecting women's autonomy makes the same kind of moral claim to conscience as does a physician who refuses to provide abortion on the basis of respect for the sanctity of life of the fetus" [10].

Importantly, decisions taken in conscience are not simply idiosyncratic; they do not rest on intuition or emotion. Rather, such decisions are based on "substantive, coherent, and reasonably stable" values and principles [10]. Physicians must be able to articulate how those values and principles justify the action in question.

The ethical arguments offered for more than two decades by those who support and those who oppose physician participation in assisted suicide reflect the diverging "substantive, coherent, and reasonably stable" values and principles within the profession and the wider moral community. While supporters and opponents of physician-assisted suicide share a common commitment to "compassion and respect for human dignity and rights" (AMA <u>Principles of Medical Ethics</u>, I), they draw different moral conclusions from the underlying principle they share. As psychiatrist Harvey Chochinov observed with respect to the stakeholders interviewed by Canadian Supreme

 Court's advisory panel on physician-assisted death, "neither those who are strongly supportive nor those who are opposed hold a monopoly on integrity and a genuine concern for the well-being of people contemplating end of life. Equally true: neither side is immune from impulses shaped more by ideology than a deep and nuanced understanding of how to best honor and address the needs of people who are suffering" [11].

THE RISK OF UNINTENDED CONSEQUENCES

From the earliest days of the debate, a prominent argument raised against permitting physician-assisted suicide has been that doing so will have adverse consequences for individual patients, the medical profession, and society at large. Scholars have cited the prospect that boundaries will be eroded and practice will be extended beyond competent, terminally ill adult patients; to patients with psychiatric disorders, children; or that criteria will be broadened beyond physical suffering to encompass existential suffering; or that stigmatized or socioeconomically disadvantaged patients will be coerced or encouraged to end their lives. Concerns have also been expressed that permitting the practice will compromise the integrity of the profession, undermine trust, and harm the physicians and other health care professionals who participate; and that forces outside medicine will unduly influence decisions.

 The question whether safeguards—which in the U.S. jurisdictions that permit assisted suicide, restrict the practice to terminally ill adult patients who have decision-making capacity and who voluntarily request assisted suicide, along with procedural and reporting requirements—can actually protect patients and sustain the integrity of medicine remains deeply contested. Some studies have "found no evidence to justify the grave and important concern often expressed about the potential for abuse—namely, the fear that legalized physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups" [12], others question whether the available data can in fact support any such conclusions, finding the evidence cited variously flawed [13], inadequate [14], or distorted [15].

Although cross-cultural comparisons are problematic [16], current evidence from Europe does tell a cautionary tale. Recent findings from studies in Belgium and the Netherlands, both countries that permit euthanasia as well as physician-assisted suicide, mitigate some fears but underscore others [17]. For example, research in the Netherlands has found that "requests characterized by psychological as opposed to physical suffering were more likely to be rejected, as were requests by individuals who lived alone," mitigating fears that "solitary, depressed individuals with potentially reversible conditions might successfully end their lives." At the same time, however, among patients who obtained euthanasia or assisted suicide, nearly 4 percent "reported only psychological suffering." At the level of anecdote, a description of a case of euthanasia in Belgium elicited widespread concern about the emergence of a "slippery slope" [18].

Studies have also raised questions about how effective retrospective review of decisions to provide euthanasia/assisted suicide is in policing practice [19,20]. A qualitative analysis of cases that Dutch regional euthanasia committees determined had not met legal "due care criteria" found that such reviews focus on procedural considerations and do not "directly assess the actual eligibility" of the patients who obtained euthanasia [19]. A separate study of cases in which psychiatric patients obtained euthanasia found that physicians' reports "stated that psychosis or depression did or did not affect capacity but provided little explanation regarding their judgments" and that review committees "generally accepted the judgment of the physician performing EAS [euthanasia or physician-assisted suicide]" [20]. It remains an open question whether reviews that are not able to assess physicians' reasoning truly offer the protection they are intended to provide. To the extent

that reporting and data collection in states that permit physician-assisted suicide have similar limitations, oversight of practice may not be adequate.

Medicine must learn from this experience. Where physician-assisted suicide is legalized, safeguards can and should be improved—e.g., "[t]o increase safeguards, states could consider introducing multidisciplinary panels to support patients through the entire process, including verifying consent and capacity, ensuring appropriate psychosocial counseling, and discussing all palliative and end-of-life options" [21]. Both the state and the medical profession have a responsibility to monitor ongoing practice in a meaningful way and to address promptly compromises in safeguards should any be discovered. It is equally important that strong practices be identified and encouraged across all jurisdictions that permit physicians to assist suicide. Health care organizations in California and Canada, for example, have shared richly descriptive reports of practices adopted in response to the recent legalization of "aid in dying" in those jurisdictions that seek to address concerns about quality of practice and data collection [22,23].

Medicine must also acknowledge, however, that evidence (no matter how robust) that there have not yet been adverse consequences cannot guarantee that such consequences would not occur in the future. As a recent commentary noted, "[p]art of the problem with the slippery slope is you never know when you are on it" [17].

SAFEGUARDING DECISIONS AT THE END OF LIFE

CEJA has found that just as there are shared commitments behind deep differences regarding physician-assisted suicide, there are also shared concerns about how to understand the available evidence. For example, in the council's recent Open Forum, both proponents and opponents of physician-assisted suicide observed that in the U.S., debate occurs against the backdrop of a health care system in which patients have uneven access to care, including access to high quality end-of-life care. They also noted that patients and physicians too often still do not have the conversations they should about death and dying, and that too few patients are aware of the range of options for end-of-life care, raising concern that many patients may be led to request assisted suicide because they don't understand the degree of relief of suffering state-of-the-art palliative care can offer. Participants who in other respects held very different views concurred as well that patients may be vulnerable to coercion, particularly patients who are in other ways disadvantaged; and expressed concern in common that forces external to medicine could adversely influence practice.

 These are much the same concerns the Institute of Medicine identified in its 2015 report, *Dying in America* [24]. They are concerns echoed in a February 2018 workshop on physician-assisted death convened by the National Academies of Science, Engineering and Medicine [25]. They underscore how important it is to understand *why* a patient requests assisted suicide as a starting point for care [26].

Patient requests for assisted suicide invite physicians to have the kind of difficult conversations that are too often avoided. They open opportunities to explore the patient's goals and concerns, to learn what about the situation the individual finds intolerable and to respond creatively to the patient's needs other than providing the means to end life—by such means as better managing symptoms, arranging for psychosocial or spiritual support, treating depression, and helping the patient to understand more clearly how the future is likely to unfold [5,27]. Medicine as a profession must ensure that physicians are skillful in engaging in these difficult conversations and knowledgeable about the options available to terminally ill patients [28]. The profession also has a responsibility to advocate for adequate resources for end-of-life care [16,28], particularly for patients from

disadvantaged groups. The availability of assisted suicide where it is legal must not be allowed to interfere with excellent care at the end of life.

CONCLUSION

At the core of public and professional debate, the council believes, is the aspiration that every patient come to the end of life as free as possible from suffering that does not serve the patient's deepest self-defining beliefs and in the presence of trusted companions, including where feasible and when the patient desires, the presence of a trusted physician. As Timothy Quill noted more than 20 years ago, "dying patients do not have the luxury of choosing not to undertake the journey, or of separating their person from their disease" [27]. Decisions about how to approach the end of life are among the most intimate that patients, families, and their physicians make. Respecting the intimacy and the authenticity of those relationships is essential if our common ideal is to be achieved.

While supporters and opponents of physician-assisted suicide share a common commitment to "compassion and respect for human dignity and rights" (<u>AMA Principles of Medical Ethics</u>, I), they draw different moral conclusions from the underlying principle they share. Where one physician understands providing the means to hasten death to be an abrogation of the physician's fundamental role as healer that forecloses any possibility of offering care that respects dignity, another in equally good faith understands supporting a patient's request for aid in hastening a foreseen death to be an expression of care and compassion.

RECOMMENDATION

The Council on Ethical and Judicial Affairs has reviewed the literature and received thoughtful input from numerous individuals and organizations to inform its deliberations, and is deeply grateful to all who shared their insights. CEJA engaged in extensive, often passionate discussion about how to interpret the *Code of Medical Ethics* in light of ongoing debate and the irreducible differences in moral perspectives identified above. The council recognized that supporters and opponents share a fundamental commitment to values of care, compassion, respect, and dignity, but diverge in drawing different moral conclusions from those underlying values in equally good faith. The council further recognized that medicine must learn from experience of physician-assisted suicide, and must ensure that, where the practice is legal, safeguards are improved.

 After careful consideration, CEJA concludes that in existing opinions on physician-assisted suicide and the exercise of conscience, the *Code* offers guidance to support physicians and the patients they serve in making well-considered, mutually respectful decisions about legally available options for care at the end of life in the intimacy of a patient-physician relationship.

Because Opinion E-5.7 powerfully expresses the perspective of those who oppose physician-assisted suicide, and Opinion E-1.1.7 articulates the thoughtful moral basis for those who support assisted suicide, the Council on Ethical and Judicial Affairs recommends that the *Code of Medical Ethics* not be amended, that Resolutions 15-A-16 and 14-A-17 not be adopted, and that the remainder of the report be filed.¹

Fiscal Note: None.

¹ CEJA plans to present E-5.7 and E-1.1.7 in online and print versions of the *Code of Medical Ethics* as suggested in the Appendix.

REFERENCES

- 1. Council on Ethical and Judicial Affairs. Decisions near the end of life. *JAMA* 1992;267:2229–2233.
- 2. Vamos MJ. Physician-assisted suicide: saying what we mean and meaning what we say. *ANZJP* 2012;46:84–86.
- 3. Herx L. Physician-assisted death is not palliative care. Curr Oncol 2015;22:82–83.
- American Association of Suicidology. "Suicide" Is Not the Same as "Physician Aid in Dying". November 12, 2017. Available at http://www.suicidology.org/Portals/14/docs/Press%20Release/AAS%20PAD%20Statement%20Approved%2010.30.17%20ed%2010-30-17.pdf. Accessed July 10, 2018.
- 5. Quill TE, Back AL, Block SD. Responding to patients requesting physician-assisted death: physician involvement at the very end of life. JAMA 2016;315:245–246.
- 6. American Academy of Hospice and Palliative Medicine. *Statement on Physician-Assisted Dying*, June 24, 2016. Available at http://aahpm.org/positions/pad. Accessed February 3, 2017.
- 7. Quill TE, Cassel CK. Professional organizations' position statements on physician-assisted suicide: a case for studied neutrality. *Ann Intern Med* 2003;138:208–211.
- 8. Sulmasy DP, Finlay I, Fitzgerald F, et al. Physician-assisted suicide: why neutrality by organized medicine is neither neutral nor appropriate. *J Gen Intern Med.* 2018;33(8):1394–1399.
- 9. Johnstone M-J. Organization position statements and the stance of "studied neutrality" on euthanasia in palliative care. *J Pain Symptom Manage* 2012;44:896–907.
- Crigger BJ, McCormick PW, Brotherton SL, Blake V. Report by the American Medical Association's Council on Ethical and Judicial Affairs on physicians' exercise of conscience. J Clin Ethics 2016;27:291–226.
- 11. Chochinov HM. Physician-assisted death in Canada. JAMA 2016;315:253–254.
- 12. Battin MP, van der Heide A, Ganzini L, van der Wal G, Onwuteaka-Philipsen B. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in vulnerable groups. *J Med Ethics* 2007;33:591–597.
- 13. Finlay IG, George R. Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups—another perspective on Oregon's data. *J Med Ethics* 2010;37:171–174.
- 14. Golden M, Zoanni T. Killing us softly: the dangers of legalizing assisted suicide. *Disability and Health Journal* 2010;3:16–30.
- 15. U.S. Conference of Catholic Bishops. *Assisted Suicide Laws in Oregon and Washington: What Safeguards?* September 22, 2016. Available at http://www.usccb.org/search.cfm?site=newusccb&proxystylesheet=newusccb_frontend&q=assisted+suicide&lang=eng. Accessed October 27, 2016.
- 16. Ganzini L, Back AL. The challenge of new legislation on physician-assisted death. *JAMA Intern Med* 2016;176:427–428.
- 17. Lerner BH, Caplan AL. Euthanasia in Belgium and the Netherlands: on a slippery slope? *JAMA Intern Med* 2015;175:1640–1641.
- 18. Aviv R. The death treatment. New Yorker;2015:June 22.
- 19. Miller DG, Kim SYH. Euthanasia and physician-assisted suicide not meeting due care criteria in the Netherlands: a qualitative review of review committee judgments. *BMJ Open* 2017;7: e017628.
- 20. Doernberg SN, Peteet JR, KIM SYH. Capacity evaluation of psychiatric patients requesting assisted death in the Netherlands. *Psychosomatics* 2016;57:556–565.
- 21. Gostin LO, Roberts AE. Physician-assisted dying: a turning point? JAMA 2016;315:249–250.

- 22. Nguyen HQ, Gelman EJ, Bush TA, Lee JA, Kanter MH. Characterizing Kaiser Permanente Southern California's experience with the California End of Life Option Act in the first year of implementation [research letter]. *JAMA Intern Med* 2017;December 26.
- 23. Li M, Watt S, Escaf M, et al. Medical assistance in dying: implementing a hospital-based program in Canada. *N Engl J Med* 2017;376:2082–2088.
- 24. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life.* Washington, DC: The National Academies Press; 2015.
- 25. National Academies of Science, Engineering and Medicine. *Physician-Assisted Death: Scanning the Landscape and Potential Approaches*. Available at https://www.nap.edu/download/25131#. Accessed August 20, 2018.
- 26 Dzeng E. Can growing popular support for physician-assisted death motivate organized medicine to improve end-of-life care? *J Gen Intern Med.* 2018;33:1209–1211.
- 27. Quill TE. Doctor, I want to die. will you help me? *JAMA* 1993;270:870–873.
- 28. Petrillo LA, Dzeng E, Smith AK. California's End of Life Option Act: opportunities and challenges ahead. *J Gen Intern Med* 2016;31:828–829.

APPENDIX

Thoughtful, morally admirable individuals hold diverging, yet equally deeply held and well-considered perspectives about physician-assisted suicide. Nonetheless, at the core of public and professional debate about physician-assisted suicide is the aspiration that every patient come to the end of life as free as possible from suffering that does not serve the patient's deepest self-defining beliefs. Supporters and opponents share a fundamental commitment to values of care, compassion, respect, and dignity; they diverge in drawing different moral conclusions from those underlying values in equally good faith.

Guidance in the AMA Code of Medical Ethics encompasses the irreducible moral tension at stake for physicians with respect to participating in assisted suicide. Opinion E-5.7 powerfully expresses the perspective of those who oppose physician-assisted suicide. Opinion 1.1.7 articulates the thoughtful moral basis for those who support assisted suicide.

5.7 Physician-Assisted Suicide

Physician-assisted suicide occurs when a physician facilitates a patient's death by providing the necessary means and/or information to enable the patient to perform the life-ending act (e.g., the physician provides sleeping pills and information about the lethal dose, while aware that the patient may commit suicide).

It is understandable, though tragic, that some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life. However, permitting physicians to engage in assisted suicide would ultimately cause more harm than good.

Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks.

Instead of engaging in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Physicians:

- (a) Should not abandon a patient once it is determined that cure is impossible.
- (b) Must respect patient autonomy.
- (c) Must provide good communication and emotional support.
- (d) Must provide appropriate comfort care and adequate pain control.

AMA Principles of Medical Ethics: I, IV

1.1.7 Physician Exercise of Conscience

Physicians are expected to uphold the ethical norms of their profession, including fidelity to patients and respect for patient self-determination. Yet physicians are not defined solely by their profession. They are moral agents in their own right and, like their patients, are informed by and

CEJA Rep. 2-A-19 -- page 10 of 11

committed to diverse cultural, religious, and philosophical traditions and beliefs. For some physicians, their professional calling is imbued with their foundational beliefs as persons, and at times the expectation that physicians will put patients' needs and preferences first may be in tension with the need to sustain moral integrity and continuity across both personal and professional life.

Preserving opportunity for physicians to act (or to refrain from acting) in accordance with the dictates of conscience in their professional practice is important for preserving the integrity of the medical profession as well as the integrity of the individual physician, on which patients and the public rely. Thus physicians should have considerable latitude to practice in accord with well-considered, deeply held beliefs that are central to their self-identities.

Physicians' freedom to act according to conscience is not unlimited, however. Physicians are expected to provide care in emergencies, honor patients' informed decisions to refuse life-sustaining treatment, and respect basic civil liberties and not discriminate against individuals in deciding whether to enter into a professional relationship with a new patient.

In other circumstances, physicians may be able to act (or refrain from acting) in accordance with the dictates of their conscience without violating their professional obligations. Several factors impinge on the decision to act according to conscience. Physicians have stronger obligations to patients with whom they have a patient-physician relationship, especially one of long standing; when there is imminent risk of foreseeable harm to the patient or delay in access to treatment would significantly adversely affect the patient's physical or emotional well-being; and when the patient is not reasonably able to access needed treatment from another qualified physician.

In following conscience, physicians should:

- (a) Thoughtfully consider whether and how significantly an action (or declining to act) will undermine the physician's personal integrity, create emotional or moral distress for the physician, or compromise the physician's ability to provide care for the individual and other patients.
- (b) Before entering into a patient-physician relationship, make clear any specific interventions or services the physician cannot in good conscience provide because they are contrary to the physician's deeply held personal beliefs, focusing on interventions or services a patient might otherwise reasonably expect the practice to offer.
- (c) Take care that their actions do not discriminate against or unduly burden individual patients or populations of patients and do not adversely affect patient or public trust.
- (d) Be mindful of the burden their actions may place on fellow professionals.
- (e) Uphold standards of informed consent and inform the patient about all relevant options for treatment, including options to which the physician morally objects.
- (f) In general, physicians should refer a patient to another physician or institution to provide treatment the physician declines to offer. When a deeply held, well-considered personal belief leads a physician also to decline to refer, the physician should offer impartial guidance to patients about how to inform themselves regarding access to desired services.

CEJA Rep. 2-A-19 -- page 11 of 11

(g) Continue to provide other ongoing care for the patient or formally terminate the patient-physician relationship in keeping with ethics guidance.

AMA Principles of Medical Ethics: I, II, IV, VI, VIII, IX

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 3-A-19

Subject: CEJA's Sunset Review of 2009 House Policies

Presented by: James E. Sabin, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William C. Reha, MD, MBA, Chair)

At its 1984 Interim Meeting, the House of Delegates (HOD) established a sunset mechanism for House policies (Policy G-600.110). Under this mechanism, a policy established by the House

ceases to be viable after 10 years unless action is taken by the House to retain it.

3 4 5

6

7

8

1 2

The objective of the sunset mechanism is to help ensure that the American Medical Association (AMA) policy database is current, coherent, and relevant. By eliminating outmoded, duplicative, and inconsistent policies, the sunset mechanism contributes to the ability of the AMA to communicate and promote its policy positions. It also contributes to the efficiency and effectiveness of HOD deliberations.

9 10 11

At its 2012 Annual Meeting, the House modified Policy G-600.110 to change the process through which the policy sunset review is conducted. The process now includes the following steps:

12 13 14

15

16

17

18

19

20

- Each year the House policies that are subject to review under the policy sunset mechanism are identified.
- Policies are assigned to appropriate Councils for review.
- For the Annual Meeting of the House, each Council develops a separate policy sunset report that recommends how each policy assigned to it should be handled. For each policy it reviews, a Council may recommend one of the following actions: (a) retain the policy; (b) sunset the policy; (c) retain part of the policy; d) reconcile the policy with more recent and like policy. A justification must be provided for the recommended action to retain a policy.

21 22 23

24

A policy will typically sunset after ten years unless action is taken by the House of Delegates to retain it. A reaffirmation or amendment to policy by the House of Delegates resets the sunset clock, making the reaffirmed or amended policy viable for another 10 years.

25262728

29

Although the policy sunset review mechanism may not be used to change the meaning of AMA policies, minor editorial changes can be accomplished through the sunset review process.

^{*}Reports of the Council on Ethical and Judicial Affairs are assigned to the reference committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

1	2009 POLICIES
2	
3	In this report, the Council on Ethical and Judicial Affairs (CEJA) presents its recommendations
4	regarding the disposition of 2009 House policies that were assigned to or originated from CEJA.
5	
6	DUPLICATIVE POLICIES
7	
8	On the model of the Council on Long Range Planning & Development (CLRPD)/CEJA Joint
9	Report I-01 and of subsequent reports of CEJA's sunset review of House policies, this report
10	recommends the rescission of House policies issued since June 2009. As noted previously, the
11	intent of this process is the elimination of duplicative ethics policies from PolicyFinder. The
12	process does not diminish the substance of AMA policy in any sense. Indeed, CEJA Opinions are a
13	category of AMA policy.
14	
15	MECHANISM TO ELIMINATE DUPLICATIVE ETHICS POLICIES
16	
17	The Council continues to present reports to the HOD. If adopted, the recommendations of these
18	reports continue to be recorded in PolicyFinder as House policy. After the corresponding CEJA
19	Opinion is issued, CEJA utilizes its annual sunset report to rescind the duplicative House policy.
20	
21	For example, at the 2007 Interim Meeting, the HOD adopted the recommendations of CEJA Report
22	8-I-07, "Pediatric Decision-Making." It was recorded in PolicyFinder as Policy H-140.865. At the
23	2008 Annual Meeting, CEJA filed the corresponding Opinion E-2.026, thereby generating a
24	duplicative policy. Under the mechanism to eliminate duplicative ethics policies, CEJA
25	recommended the rescission of Policy H-140.865 as part of the Council's 2009 sunset report.
26	
27	The Appendix provides recommended actions and their rationale on House policies from 2009, as
28	well as on duplicate policies.
29	
30	RECOMMENDATION
31	
32	The Council on Ethical and Judicial Affairs recommends that the House of Delegates policies that
33	are listed in the Appendix to this report be acted upon in the manner indicated and the remainder of
34	this report be filed. (Directive to Take Action)

Fiscal Note: Less than \$500.

APPENDIX - RECOMMENDED ACTIONS

Policy No.	Title	Recommended Action & Rationale
D-105.998	Direct to Consumer Advertising D-105.998	Rescind The goal of this directive was accomplished through AMA communication to the Food and Drug Administration. Policy H- 105.988, Direct-to-Consumer Advertising (DTCA) of Prescription Drugs and Implantable Devices to which it refers remains in effect.
D-250.991	Victims of the War in Kosovo	Rescind. Policy is outdated. The goal of this directive was originally accomplished by the establishment of the Physician Opportunities Portal, which has been discontinued.
D-250.992	Medical Supply Donations to Foreign Countries	Rescind. Policy is outdated and duplicates efforts of the World Health Organization, which provides upto-date international information and guidelines on humanitarian donations of medical supplies at https://www.who.int/hac/crises/hti/appeal/medical_supplies/en/ .
D-315.994	Abuse of the Medical Record for Regulation or Financing the Practice of Medicine	Rescind The goal of this directive is accomplished through extensive materials available at https://www.ama-assn.org/search?search=confidentiality%2C+medical+records&sort-by=search-api-relevance
D-315.996	Interim Report of the Inter-Council Task Force on Privacy and Confidentiality	Rescind The goal of this directive is accomplished by extensive materials available at https://policysearch.ama-assn.org/policyfinder/search/HIPAA/relevant/1/
D-373.998	Guidelines for Handling Derogatory Conduct in the Patient-Physician Relationship	Rescind The goal of this directive was accomplished in AMA correspondence to the Joint

	T	T ~
		Commission and directive is
		duplicative of <u>E-1.2.2</u> , Disruptive
		Behavior by Patients. This issue
		is currently under further
		consideration by the Council on
		Ethical and Judicial Affairs in
		response to Resolution 18-A-18.
D-460.974	Office for Human Research Protections	Rescind
D 400.774	Interpretation of 45 CFR Part 46	The goal of this directive was
	interpretation of 43 Cr K r art 40	accomplished in AMA
		correspondence with the Office of
		Human Research Protections and
		has been superseded by the
		revised Common Rule (2017).
D-460.991	Interim Report of the Inter-Council Task Force on	Rescind
	Privacy and Confidentiality	This directive is outdated and is
		superseded by the revised
		Common Rule (2017).
D-60.970	Disclosure of Health Status to Children and	Rescind
	Adolescents	The goal of this directive was
		accomplished by amendments to
		E-2.1.1, Pediatric Decision
		Making, adopted in 2010, 2018.
D-70.954	Transition to ICD-10 Code Sets	Rescind
D-70.754	Transition to ICD-10 Code Sets	The goal of this directive is
		accomplished by extensive
		material available at
		https://www.ama-
VI 7 000	D 11	assn.org/search?search=ICD-10
H-5.990	Policy on Abortion	Reaffirm
H-65.985	Inappropriate Federal Prosecution	Reaffirm
H-140.921	Preserving the Traditional Patient-Physician	Rescind
	Relationship	Policy is outdated and duplicative
		of guidance in the modernized
		Code of Medical Ethics (2016):
		E-8.6, Promoting Patient Safety
		E-9.5.2, Staff Privileges
		E-10.1, Ethics Guidance for
		Physicians in Nonclinical Roles
		E-11.2.1 Professionalism in
		Health Care Systems
		E-11.2.2, Conflicts of Interest in
		Patient Care
		E-11.2.3, Contracts to Deliver
		Health Care Services
		E-11.2.4, Transparency in Health
		Care
H-140.926	Policy for Physician Entrepreneur Activity	Reaffirm
H-140.949	Physician-Assisted Suicide	Rescind

		Title is misleading in that this
		policy, originally adopted in
		1996, focuses on palliative care,
		not physician-assisted suicide.
		AMA has subsequently
		developed extensive policy in this
		area:
		H-70.915, Good Palliative Care
		(2014)
		H-295.875, Palliative Care and
		End of Life Care (2006)
		H-85.951, Concurrent Hospice
		and Curative Care (2016)
		H-85.955, Hospice Care (2014)
		D-600.984 Specialty Organizations Seated in our
		•
		AMA House of Delegates (2018),
		seating the American Academy of
		Hospice and Palliative Medicine
		E-5.1, Advance Care Planning
H 140.052	Dissision Assists I Caristia	(2010)
H-140.952	Physician Assisted Suicide	Reaffirm
H-140.951	Professionalism and Medical Ethics	Consolidate and retitle:
H-140.996	Reaffirmation of Professionalism	H-140.951 Professionalism in
	D 6 ' 1' 174' 174' 174'	Medicine
	Professionalism and Medical Ethics H-140.951	Our AMA believes that the
	The AMA reaffirms that the medical profession is	primary mission of the physician
	solely responsible for establishing and	is to use his best efforts and skill
	maintaining standards of professional medical	in the care of his patients and to
	ethics and that the state cannot legislate ethical	be mindful of those forces in
	standards or excuse physicians from their ethical	society that would erode
	obligations; and urges all physicians and other	fundamental ethical medical
	appropriate health professional organizations to	practice. The AMA affirms that
	make their views known to their state legislatures	the medical profession is solely
	and governors.	responsible for establishing and
	D 66" 4' 6D 6 ' 1' 11 140 004	maintaining standards of
	Reaffirmation of Professionalism H-140.996	professional medical ethics and
	Our AMA believes that the primary mission of the	that the state neither legislate
	physician is to use his best efforts and skill in the	ethical standards nor excuse
	care of his patients and to be mindful of those	physicians from their ethical
	forces in society that would erode fundamental	obligations. The AMA House of
	ethical medical practice. The AMA House of	Delegates, Board of Trustees,
	Delegates, Board of Trustees, staff, and	staff, and membership rededicate
	membership rededicate themselves to	themselves to professionalism
	professionalism such that it permeates all	such that it permeates all
	activities and is the defining characteristic of the	activities and is the defining
	AMA's identity.	characteristic of the AMA's
		identity.
H-190.958	Readability of Medical Notices of Privacy	Rescind
	Practices	AMA provides sample language
		for notice of privacy practices at

		https://www.ama-
		assn.org/practice-
		management/hipaa/hipaa-privacy-
II 215 007	D. C.	security-resources
H-315.997	Patients' Access to Information Contained in	Rescind
	Medical Records	Policy is outdated. HIPAA
		mandates patient access to their
		medical records.
H-315.998	Medical Record Privacy	Rescind.
		Policy adopted in 1979 is
		superseded by more recent law
		and regulation. AMA model
		legislation on this issue is no
		longer publicly available.
H-350.971	Initiatives Regarding Minorities	Defer recommendation to 2019
H-350.975	Improving Healthcare of Hispanic Populations in	Interim meeting pending review
	the United States	by Chief Health Equity Officer.
		Consider consolidating these and
		other policies that address
		identified patient populations and
		health disparities:
		1
		H-160.991 Health Care Needs of
		Gay, Lesbian, Bisexual and
		Transgender Populations
		Transgender roparations
		H-295.878 Eliminating Health
		Disparities—Promoting
		Awareness and Education of
		Lesbian, Gay, Bisexual and
		Transgender (LGBT) Issues in
		Medical Education
		<u>Wedical Education</u>
		H-350.957 Addressing Immigrant
		Health Disparities
		Health Dispartites
		H-350.958 Hispanic Population
		and Access to the US Healthcare
		System
		H 250 050 Guiding Principles for
		H-350.959 Guiding Principles for
		Eliminating Racial and Ethnic
		Health Care Disparities
		II 250 061 Immersion the Health
		H-350.961 Improving the Health
		of Minority Populations
		H 250 066 H-1dt 1-1d 1
		H-350.966 Health Initiatives on
		Asian-Americans and Pacific
		<u>Islanders</u>

		H-350.971 AMA Initiatives Regarding Minorities H-350.972 Improving the Health of Black and Minority Populations
		H-350.974 Racial and Ethnic Disparities in Health Care
		H-350.976 Improving Health Care of American Indians
		H-440.869 Establishment of State Commission/Task Force to Eliminate Racial and Ethnic Health Care Disparities
		D-350.996 Strategies for Eliminating Minority Health Care disparities
		D-55.997 Cancer and Health Care Disparities among Minority Women
		D-65.995 Health Care Disparities among Gay, Lesbian, Bisexual and Transgender Families
H-405.982	Medical Informatics - Policy Initiatives for the AMA	Rescind Superseded by AMA digital health resources at https://www.ama- assn.org/search?search=digital+h ealth
H-515.967	Protection of the Privacy of Sexual Assault Victims	Reaffirm

Resolution: 001

(A-19)

Introduced by: Illinois

Subject: Opposing Attorney Presence at and/or Recording of Independent Medical

Examinations

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, An independent medical examination or IME (also known as a compulsory medical examination or CME) is an integral component used in civil litigation to resolve questions about a particular medical condition or care; and

Whereas, Recording, videotaping, or allowing the presence of a court reporter or opposing attorney during the IME can, simply by their presence, obstruct efforts to properly obtain medical information and can create an adversarial environment; and

Whereas, Courts are increasingly compelling physicians to agree to the above conditions as a condition to testifying; and

Whereas, No other professionals are compelled to agree to these conditions as a condition to testifying; and

Whereas, Any significant collateral medical issue discovered during the IME must be disclosed to the patient, and thus a partial patient-physician relationship actually does exist; and

Whereas, The recording of the IME is the property of the legal representative of the person being examined and can be used in future trials or venues as they see fit; therefore be it

RESOLVED, That our American Medical Association amend Policy H-365.981, "Workers' Compensation," by addition to read as follows:

Our AMA:

- (1) will promote the development of practice parameters, when appropriate, for use in the treatment of injured workers and encourages those experienced in the care of injured workers to participate in such development.
- (2) will investigate support for appropriate utilization review guidelines for referrals, appropriate procedures and tests, and ancillary services as a method of containing costs and curbing overutilization and fraud in the workers' compensation system. Any such utilization review should be based on open and consistent review criteria that are acceptable to and have been developed in concert with the medical profession. Physicians with background appropriate to the care under review should have the
- Physicians with background appropriate to the care under review should have the ultimate responsibility for determining quality and necessity of care.
- (3) encourages the use of the Guides to the Evaluation of Permanent Impairment. The correct use of the Guides can facilitate prompt dispute resolution by providing a single, scientifically developed, uniform, and objective means of evaluating medical impairment.

Resolution: 001 (A-19)

Page 2 of 2

- (4) encourages physicians to participate in the development of workplace health and safety programs. Physician input into healthy lifestyle programs (the risks associated with alcohol and drug use, nutrition information, the benefits of exercise, for example) could be particularly helpful and appropriate.
 - (5) encourages the use of uniform claim forms (CMS 1500, UB04), electronic billing (with appropriate mechanisms to protect the confidentiality of patient information), and familiar diagnostic coding guidelines (ICD-9-CM, CPT; ICD-10-CM, CPT), when appropriate, to facilitate prompt reporting and payment of workers' compensation claims.
 - (6) will evaluate the concept of Independent Medical Examinations (IME) and make recommendations concerning IME's (i) effectiveness; (ii) process for identifying and credentialing independent medical examiners; and (iii) requirements for continuing medical education for examiners.
 - (7) encourages state medical societies to support strong legislative efforts to prevent fraud in workers' compensation.
 - (8) will continue to monitor and evaluate state and federal health system reform proposals which propose some form of 24-hour coverage.
 - (9) will continue to evaluate these and other medical care aspects of workers' compensation and make timely recommendations as appropriate.
 - (10) will continue activities to develop a unified body of policy addressing the medical care issues associated with workers' compensation, disseminate information developed to date to the Federation and provide updates to the Federation as additional relevant information on workers' compensation becomes available.

 (11) opposes the ability of courts to compel recording and videotaping of, or allow a
 - court reporter or an opposing attorney to be present during, the independent medical examination, as a condition for the physician's medical opinions to be allowed in court.

 (Modify Current HOD Policy): and be it further

27 (Modify Current HOD Policy); and be it further

RESOLVED, That revised AMA Policy H-365.981, "Workers Compensation," be included in the AMA's *Guide to the Evaluation of Permanent Impairment*. (New HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 03/20/19

Resolution: 002

(A-19)

Introduced by: Minnesota

Subject: Addressing Existential Suffering in End-of-Life Care

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, The duty to relieve pain and suffering is central to the physician's role as healer; and

Whereas, Patients may experience both physical and existential suffering at the end-of-life; and

Whereas, Sedation to unconsciousness is an ethical practice to address refractory clinical symptoms, but is inappropriate to respond to existential suffering; and

Whereas, Existential suffering includes anxiety, isolation, loss of control, and other non-physical suffering that are serious conditions impacting patients' health; and

Whereas, Pharmacological or other clinical options short of sedation to unconsciousness may be appropriate to mitigate a patient's existential suffering; and

Whereas, Physicians have an ethical obligation to respect and consider the previously expressed wishes of a patient who has lost the ability to provide consent; and

Whereas, Existing AMA Council on Ethical and Judicial Affairs Opinion 5.6 addresses many of these issues in detail but does not expressly address two areas; and

Whereas, CEJA Opinion 5.6 states that existential suffering should be addressed through social, psychological, or spiritual support to the exclusion of other clinical options, even though there are treatments for existential suffering beyond social, psychological or spiritual support that are beneficial for patients; and

Whereas, CEJA Opinion 5.6 states that consent must be obtained from the patient or surrogate, but does not recognize or require consideration of a patient's previously expressed wishes in the case of surrogate decision making; therefore be it

RESOLVED, That our American Medical Association ask the Council on Judicial and Ethical affairs to review Ethical Opinion 5.6, "Sedation to Unconsciousness in End-of-Life Care," to address the following two issues: appropriate treatments beyond social, psychological or spiritual support to treat existential suffering, and the recognition of a patient's previously expressed wishes with end-of-life care. (Directive to Take Action)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 04/24/19

Resolution: 002 (A-19)

Page 2 of 2

References:

1. N Kirk, T. W., & Mahon, M. M. (2010). National Hospice and Palliative Care Organization (NHPCO) position statement and commentary on the use of palliative sedation in imminently dying terminally ill patients. Journal of pain and symptom management, 39(5), 914-923.

2. American Academy of Hospice and Palliative Medicine Statement on Palliative Sedation, http://aahpm.org/positions/palliative-sedation.

RELEVANT AMA POLICY

E-5.6 Sedation to Unconsciousness in End-of-Life Care

The duty to relieve pain and suffering is central to the physicians role as healer and is an obligation physicians have to their patients. When a terminally ill patient experiences severe pain or other distressing clinical symptoms that do not respond to aggressive, symptom-specific palliation it can be appropriate to offer sedation to unconsciousness as an intervention of last resort.

Sedation to unconsciousness must never be used to intentionally cause a patients death. When considering whether to offer palliative sedation to unconsciousness, physicians should:

- (a) Restrict palliative sedation to unconsciousness to patients in the final stages of terminal illness.
- (b) Consult with a multi-disciplinary team (if available), including an expert in the field of palliative care, to ensure that symptom-specific treatments have been sufficiently employed and that palliative sedation to unconsciousness is now the most appropriate course of treatment.
- (c) Document the rationale for all symptom management interventions in the medical record.
- (d) Obtain the informed consent of the patient (or authorized surrogate when the patient lacks decision-making capacity).
- (e) Discuss with the patient (or surrogate) the plan of care relative to:
- (i) degree and length of sedation;
- (ii) specific expectations for continuing, withdrawing, or withholding future life-sustaining treatments.
- (f) Monitor care once palliative sedation to unconsciousness is initiated.

Physicians may offer palliative sedation to unconsciousness to address refractory clinical symptoms, not to respond to existential suffering arising from such issues as death anxiety, isolation, or loss of control. Existential suffering should be addressed through appropriate social, psychological or spiritual support.

AMA Principles of Medical Ethics: I,VII

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.

Issued: 2016

Resolution: 003

(A-19)

Introduced by: GLMA: Health Professionals Advancing LGBTQ Equality

Subject: Conforming Sex and Gender Designation on Government IDs and Other

Documents

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, The current US population of transgender adults is estimated to be about 0.6% of the US population, or about 1.4 million adults¹; and

Whereas, A 2015 U.S. Transgender Survey conducted by the National Center for Transgender Equality (NCTE) found that 68% of transgender individuals live without a valid ID that matches their gender identity²; and

Whereas, The same survey noted that nearly one third (32%) of those who showed ID that did not match their gender presentation were verbally harassed, denied benefits or service, asked to leave, or assaulted²; and

Whereas, The cost of updating gender markers and procedural requirements (such as providing documentation of medical information) are among the main barriers preventing respondents from updating the gender on their IDs and records²; and

Whereas, One in four (25%) respondents reported problems regarding medical insurance in the past year related to being transgender, such as being denied coverage for care related to gender transition²; and

Whereas, Seventeen percent (17%) of respondents had an insurer refuse to change the name and/or gender in insurance records when requested and thirteen percent (13%) reported denial of coverage for services often considered to be gender-specific, including routine sexual or reproductive health screenings (such as Pap smears, prostate exams, and mammograms)²; and

Whereas, Government issued IDs include, but are not limited to, birth certificates, passports, driver's licenses, state identification cards, and other local, state, and federally issued identification; and

Whereas, At least ten states plus New York City and the District of Columbia currently issue updated sex designations on birth certificates and/or driver's licenses without requiring documentation from a medical provider: Arkansas,³ California,⁴ District of Columbia,⁵ Idaho,⁶ Massachusetts,⁷ Minnesota,⁸ Montana,⁹ Nevada,¹⁰ New Jersey,¹¹ New York City,¹² Oregon,¹³ and Washington¹⁴; and

Whereas, At least ten states plus New York City and the District of Columbia offer birth certificates and/or driver's licenses with a gender-neutral option: California, 4 Colorado, 15

Connecticut,¹⁶ District of Columbia,⁵ Maine,¹⁷ Minnesota,¹⁸ Nevada,¹⁰ New Jersey,¹¹ New York

38 City, 12 Oregon, 19 Arkansas, 3 and Washington 14; and

Resolution: 003 (A-19) Page 2 of 4

Whereas, Our AMA has strong policy advocating for removal of barriers to change the sex designation of an individual's birth certificate (H-65.967), but has outdated requirements for the change of sex designation and does not include mention of other government IDs within this policy; therefore be it

RESOLVED, That our American Medical Association modify HOD Policy H-65.967, "Conforming Birth Certificate Policies to Current Medical Standards for Transgender Patients," by addition and deletion to read as follows:

Conforming Birth Certificate Policies to Current Medical Standards for Transgender Patients Sex and Gender Designation on Government IDs and Other Documents (H-65.967)

1. Our AMA supports policies that allow for a change of sex designation on birth certificates for transgender individuals based upon verification by a physician (MD or DO) that the individual has undergone gender transition according to applicable medical standards of care every individual's right to determine their gender identity and sex designation on government documents and other forms of government identification.

2. Our AMA supports policies that allow for a sex designation or change of designation on all government IDs to reflect an individual's gender identity, as reported by the individual and without need for verification by a medical professional.

3. Our AMA supports policies that include an undesignated or nonbinary gender option for government records and forms of government-issued identification, which would be in addition to "male" and "female."

4. Our AMA: (a) supports elimination of any requirement that individuals undergo gender affirmation surgery in order to change their sex designation on birth certificates and supports modernizing state vital statistics statutes to ensure accurate gender markers on birth certificates; and (b) supports that any change of sex designation on an individual's birth certificate not hinder access to medically appropriate preventive care supports efforts to ensure that the sex designation on an individual's government-issued documents and identification does not hinder access to medically appropriate care or other social services in accordance with that individual's needs. (Modify Existing Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/01/19

References:

- 1. The Williams Institute. https://williamsinstitute.law.ucla.edu/wp-content/uploads/How-Many-Adults-Identify-as-Transgender-in-the-United-States.pdf
- 2. James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). The Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center for Transgender Equality
- 3. Arkansas Driver Services instructions,

https://transequality.org/sites/default/files/docs/id/AR%20Drivers%20License%20gender%20change%20guidance.pdf 4. California Gender Recognition Act, SB 179,

https://leginfo.legislature.ca.gov/faces/billCompareClient.xhtml?bill_id=201720180SB179.

5. DC Gender Self-Designation Form,

https://dmv.dc.gov/sites/default/files/dc/sites/dmv/publication/attachments/DC%20DMV%20Form%20Gender%20Self -Designation%20English.pdf.

6. Idaho Division off Public Health Instructions to Change the Indicator of Sex on an Idaho Birth Certificate to Reflect Gender Identity, https://healthandwelfare.idaho.gov/Portals/0/Health/Vital%20Records/GenderChangePacket_4-18.pdf.

Resolution: 003 (A-19)

Page 3 of 4

- 7. MA Gender Designation Change Form, https://www.mass.gov/files/documents/2018/03/22/LIC108%20-%20Massachusetts%20Gender%20Designation%20Change%20Form_0.pdf.
- 8. Minnesota Driver and Vehicle Services Self-Designated Descriptors, https://dps.mn.gov/divisions/dvs/Pages/self-designated-descriptors.aspx
- 9. Montana Rule 37.8.311, Adoptions, Name Changes, and Gender Changes, http://www.mtrules.org/gateway/RuleNo.asp?RN=37.8.311
- 10. Nevada Administrative Code 440.030, https://www.leg.state.nv.us/Register/RegsReviewed/\$R066-16A.pdf. Nevada Administrative Code 483-070, and see https://dmvnv.com/namechange.htm.
- 11. New Jersey Babs Siperstein Law, https://www.njleg.state.nj.us/2018/Bills/A2000/1718_R2.PDF.
- 12. New York City Health Code Article 207, https://www1.nyc.gov/assets/doh/downloads/pdf/notice/2018/noa-amend-article207-section207-05.pdf.
- 13. Oregon Health Authority House Bill 2673 Information Sheet,

https://www.oregon.gov/oha/PH/BIRTHDEATHCERTIFICATES/CHANGEVITALRECORDS/Documents/OHA-2673.pdf; Oregon Driver & Motor Vehicle Services instructions,

https://www.oregon.gov/ODOT/DMV/Pages/driverid/chg_gender_designation.aspx.

- 14. Washington WAC 246-490-075, Changing sex designation on a birth certificate, http://app.leg.wa.gov/WAC/default.aspx?cite=246-490-075.
- 15. Colorado Change of Sex Designation, https://www.colorado.gov/pacific/sites/default/files/DR2083.pdf.
- 16. Connecticut Department of Public Health Statement, https://www.cga.ct.gov/2019/PHdata/Tmy/2019SB-00388-R000225-Department%20of%20Public%20Health-TMY.PDF.
- 17. Maine Gender Designation Form,

https://www1.maine.gov/sos/bmv/forms/GENDER%20DESIGNATION%20FORM.pdf.

- 18. MN Driver and Vehicle Services Self-Designated Descriptors, https://dps.mn.gov/divisions/dvs/Pages/self-designated-descriptors.aspx
- 19. Oregon Driver & Motor Vehicle Services instructions,

https://www.oregon.gov/ODOT/DMV/Pages/driverid/chg_gender_designation.aspx.

RELEVANT AMA POLICY

Medical Spectrum of Gender D-295.312

Given the medical spectrum of gender identity and sex, our AMA: (1) will work with appropriate medical organizations and community based organizations to inform and educate the medical community and the public on the medical spectrum of gender identity; (2) will educate state and federal policymakers and legislators on and advocate for policies addressing the medical spectrum of gender identity to ensure access to quality health care; and (3) affirms that an individual's genotypic sex, phenotypic sex, sexual orientation, gender and gender identity are not always aligned or indicative of the other, and that gender for many individuals may differ from the sex assigned at birth. Citation: Res. 003, A-17; Modified: Res. 005, I-18

Conforming Birth Certificate Policies to Current Medical Standards for Transgender Patients H-65.967

- 1. Our AMA supports policies that allow for a change of sex designation on birth certificates for transgender individuals based upon verification by a physician (MD or DO) that the individual has undergone gender transition according to applicable medical standards of care.
- 2. Our AMA: (a) supports elimination of any requirement that individuals undergo gender affirmation surgery in order to change their sex designation on birth certificates and supports modernizing state vital statistics statutes to ensure accurate gender markers on birth certificates; and (b) supports that any change of sex designation on an individual's birth certificate not hinder access to medically appropriate preventive care.

Citation: (Res. 4, A-13; Appended: BOT Rep. 26, A-14

Accuracy, Importance, and Application of Data from the US Vital Statistics System H-85.961

Our AMA encourages physicians to provide complete and accurate information on prenatal care and hospital patient records of the mother and infant, as this information is the basis for the health and medical information on birth certificates.

Citation: (CSA Rep. 6, I-00; Reaffirmed: Sub. Res. 419, A-02; Modified: CSAPH Rep. 1, A-12

Reducing Suicide Risk Among Lesbian, Gay, Bisexual, Transgender, and Questioning Youth Through Collaboration with Allied Organizations H-60.927

Our AMA will partner with public and private organizations dedicated to public health and public policy to reduce lesbian, gay, bisexual, transgender, and questioning (LGBTQ) youth suicide and improve health among LGBTQ youth.

Citation: (Res. 402, A-12

Health Care Needs of Lesbian, Gay, Bisexual, Transgender and Queer Populations H-160.991

1. Our AMA: (a) believes that the physician's nonjudgmental recognition of patients' sexual orientations, sexual behaviors, and gender identities enhances the ability to render optimal patient care in health as well as in illness. In

Resolution: 003 (A-19)

Page 4 of 4

the case of lesbian, gay, bisexual, transgender, queer/questioning, and other (LGBTQ) patients, this recognition is especially important to address the specific health care needs of people who are or may be LGBTQ; (b) is committed to taking a leadership role in: (i) educating physicians on the current state of research in and knowledge of LGBTQ Health and the need to elicit relevant gender and sexuality information from our patients; these efforts should start in medical school, but must also be a part of continuing medical education; (ii) educating physicians to recognize the physical and psychological needs of LGBTQ patients; (iii) encouraging the development of educational programs in LGBTQ Health; (iv) encouraging physicians to seek out local or national experts in the health care needs of LGBTQ people so that all physicians will achieve a better understanding of the medical needs of these populations; and (v) working with LGBTQ communities to offer physicians the opportunity to better understand the medical needs of LGBTQ patients; and (c) opposes, the use of "reparative" or "conversion" therapy for sexual orientation or gender identity.

- 2. Our AMA will collaborate with our partner organizations to educate physicians regarding: (i) the need for sexual and gender minority individuals to undergo regular cancer and sexually transmitted infection screenings based on anatomy due to their comparable or elevated risk for these conditions; and (ii) the need for comprehensive screening for sexually transmitted diseases in men who have sex with men; (iii) appropriate safe sex techniques to avoid the risk for sexually transmitted diseases; and (iv) that individuals who identify as a sexual and/or gender minority (lesbian, gay, bisexual, transgender, queer/questioning individuals) experience intimate partner violence, and how sexual and gender minorities present with intimate partner violence differs from their cisgender, heterosexual peers and may have unique complicating factors.
- 3. Our AMA will continue to work alongside our partner organizations, including GLMA, to increase physician competency on LGBTQ health issues.
- 4. Our AMA will continue to explore opportunities to collaborate with other organizations, focusing on issues of mutual concern in order to provide the most comprehensive and up-to-date education and information to enable the provision of high quality and culturally competent care to LGBTQ people.

Citation: CSA Rep. C, I-81; Reaffirmed: CLRPD Rep. F, I-91; CSA Rep. 8 - I-94; Appended: Res. 506, A-00; Modified and Reaffirmed: Res. 501, A-07; Modified: CSAPH Rep. 9, A-08; Reaffirmation A-12; Modified: Res. 08, A-16; Modified: Res. 903, I-17; Modified: Res. 904, I-17; Res. 16, A-18; Reaffirmed: CSAPH Rep. 01, I-18

Support of Human Rights and Freedom H-65.965

Our AMA: (1) continues to support the dignity of the individual, human rights and the sanctity of human life, (2) reaffirms its long-standing policy that there is no basis for the denial to any human being of equal rights, privileges, and responsibilities commensurate with his or her individual capabilities and ethical character because of an individual's sex, sexual orientation, gender, gender identity, or transgender status, race, religion, disability, ethnic origin, national origin, or age; (3) opposes any discrimination based on an individual's sex, sexual orientation, gender identity, race, religion, disability, ethnic origin, national origin or age and any other such reprehensible policies; (4) recognizes that hate crimes pose a significant threat to the public health and social welfare of the citizens of the United States, urges expedient passage of appropriate hate crimes prevention legislation in accordance with our AMA's policy through letters to members of Congress; and registers support for hate crimes prevention legislation, via letter, to the President of the United States.

Citation: CCB/CLRPD Rep. 3, A-14; Reaffirmed in lieu of: Res. 001, I-16; Reaffirmation: A-17

Nondiscriminatory Policy for the Health Care Needs of LGBTQ Populations H-65.976

Our AMA encourages physician practices, medical schools, hospitals, and clinics to broaden any nondiscriminatory statement made to patients, health care workers, or employees to include "sexual orientation, sex, or gender identity" in any nondiscrimination statement.

Citation: Res. 414, A-04; Modified: BOT Rep. 11, A-07; Modified: Res. 08, A-16; Modified: Res. 903, I-17

Access to Basic Human Services for Transgender Individuals H-65.964

Our AMA: (1) opposes policies preventing transgender individuals from accessing basic human services and public facilities in line with ones gender identity, including, but not limited to, the use of restrooms; and (2) will advocate for the creation of policies that promote social equality and safe access to basic human services and public facilities for transgender individuals according to ones gender identity.

Citation: Res. 010, A-17

Appropriate Placement of Transgender Prisoners H-430.982

- 1. Our AMA supports the ability of transgender prisoners to be placed in facilities, if they so choose, that are reflective of their affirmed gender status, regardless of the prisoners genitalia, chromosomal make-up, hormonal treatment, or non-, pre-, or post-operative status.
- 2. Our AMA supports that the facilities housing transgender prisoners shall not be a form of administrative segregation or solitary confinement.

Citation: BOT Rep. 24, A-18

Resolution: 004

(A-19)

Introduced by: New York

Subject: Reimbursement for Care of Practice Partner Relatives

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Medicare has rules that exclude Medicare payments for items and services that, Medicare deems, would be furnished gratuitously because of the relationship of the beneficiary to the person imposing the charge; and

Whereas, Chapter 16 of Medicare guidelines (130 - Charges Imposed by Immediate Relatives of the Patient or Members of the Patient's Household (Rev. 1, 10-01-03) A3-3161, HO-260.12, B3-2332) defines rules, these guidelines have not been revised since 2014; and

Whereas, The following degrees of relationship are included in definition of an immediate relative including husband and wife, natural or adoptive parents, child and sibling, stepparent, stepchild, stepbrother, stepsister, in-laws, grandparents, grandchildren and spouses of such grandparents and grandchildren; and

Whereas, Exclusion applies whether the provider is a sole proprietor who has an excluded relationship to the patient or a partnership in which even one of the partners is related to the patient; and

Whereas, Medicare makes the false assumption that a cardiologist seeing the father-in-law of an internist in his group would be compelled to provide cardiology services for free. This places the physician providing services in a difficult position where they provide services at a loss or must refuse to see the patient. This also puts the physicians, whose family member requires care, in an awkward predicament. They must either ask colleague to see their family member at a loss or tell the family member that it is not possible to be seen in their practice. Thus, this regulation strains physician-patient relationships and restricts access to trusted care; therefore be it

RESOLVED, That our American Medical Association support changes in the Medicare guidelines to allow a physician, who is a partner in the practice, to care for and receive appropriate reimbursement for immediate relatives of one of the other partners in their practice.

30 (Directive to Take Action)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 04/25/19

Resolution: 005

(A-19)

Introduced by: New York

Subject: Right for Gamete Preservation Therapies

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, A small but significant number of individuals have gender identities that differ from their genotypic and phenotypic gender; and

3 4

Whereas, An increasing number of these individuals will choose to undergo gender affirming treatment at some time during their reproductive lives; and

5 6 7

Whereas, Many transgender or non-binary individuals may desire to have children of their own just as cisgender individuals desire to have children of their own; and

8 9 10

Whereas, In order for a transgender or non-binary individual to have their own biological child, he or she generally must preserve their gametes prior to undergoing gender affirming medical and surgical therapies; therefore be it

12 13 14

11

RESOLVED, That fertility preservation services be officially recognized by our American

15 Medical Association as an option for the members of the transgender and non-binary

community who wish to preserve future fertility through gamete preservation prior to undergoing gender affirming medical or surgical therapies (New HOD Policy); and be it further

17

18 19

20

16

RESOLVED, That our AMA officially support the right of transgender or non-binary individuals to seek gamete preservation therapies. (New HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 04/25/19

Resolution: 006

(A-19)

Introduced by: Wisconsin

Subject: Use of Person-Centered Language

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Communication is one of the foundational aspects of patient care that impacts patient satisfaction and builds rapport between a physician and patient;¹ and

Whereas, Person-first language is a style of communication in which the person is listed first followed by descriptive terms, such as a disease state (e.g. "a person with schizophrenia" rather than "a schizophrenic"), which avoids defining a person by his or her disease state and places the emphasis on the person rather than the disease or disability; and

Whereas, The use of person-first language may improve the doctor-patient relationship,² encourage a healthy relationship between researchers and the community,^{3,4} and may reduce stigma associated with certain disease states;^{5,6} and

Whereas, Multiple organizations including the federal Center for Disease Control and Prevention, American Psychological Association, and American Society of Addiction Medicine encourage person-first language;^{7,8,9,10,11,12} and

Whereas, Person-centered language is a style of communication that incorporates an individual's preference and identity when referring to a disease state (e.g. "a blind person" or "a person with blindness" based on personal preference), which may deviate from person-first language; and

Whereas, The use of person-centered language focuses on each person's individual preferences rather than using generalizing terms for a group when referring to a disease state or disability, which seeks to maintain dignity and respect for all individuals; 13,14 and

Whereas, Certain groups - such as the deaf and the blind communities - speak against using person-first language because they identify their disability as a trait they possess instead of a pathologic process, and this issue is mitigated by using person-centered language;^{15,16} and

Whereas, The Canadian Alzheimer's Society has developed specific guidelines for using person-centered language as to "not diminish the uniqueness and intrinsic value of each person and to allow a full range of thoughts, feeling and experiences to be communicated," and to continue to build trusting relationships with these patients regardless of their condition; and

Whereas, The AMA recommends the use of person-first language in the AMA Code of Style, and recently adopted policy regarding the use of person-first language for obesity (H-440.821) but failed to include other disease states; therefore be it

Resolution: 006 (A-19)

Page 2 of 3

1 RESOLVED, That our American Medical Association encourage the use of person-centered

2 language. (New HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/01/19

References:

. Mohammed, K *et al.* Creating a Patient-Centered Health Care Delivery System: A Systematic Review of Health Care Quality From the Patient Perspective. Amer. J of Med. 2016; 31(1): 12-21.

- 2. Schwartz, D *et al.* Seeing the Person, Not the Illness: Promoting Diabetes Medication Adherence Through Patient-Centered Collaboration. Clin. Diabetes. 2017 Jan; 35(1): 35-42.
- 3. Tai-Seale, M *et al.* The Language of Engagement: "Aha!" Moments from Engaging Patients and Community Partners in Two Pilot Projects of the Patient-Centered Outcomes Research Institute. Perm J. 2016 Spring; 20(2): 89-92.
- 4. Wynia M and Matiasek J. Promising Practices for Patient-Centered Communication with Vulnerable Populations: Examples from Eight Hospitals. The Commonwealth Fund. 2006.
- 5. Puhl R, Peterson JL, Luedicke J. Motivating or stigmatizing? Public perceptions of weight-related language used by health providers. Int J Obes (Lond). 2013 Apr; 37(4): 612-9.
- 6. Noble AJ et al. 'Epileptic', 'epileptic person' or 'person with epilepsy'? Bringing quantitative and qualitative evidence on the views of UK patients and carers to the terminology debate. Epilepsy & Behavior 2017 Feb; 67: 20-27.
- National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. Disability Inclusion Strategies. 1 August 2017. Available at https://www.cdc.gov/ncbddd/disabilityandhealth/disability-strategies.html, Accessed 6 September 2017.
- 8. Dunn, DS and Andrews, EE. Person-first and identity-first language: Developing psychologists' cultural competence using disability language. American Psychologist 2015; 70(3): 255-264.
- 9. Botticelli MP and Koh HK. Changing the Language of Addiction. JAMA. 2016; 316(13): 1361-1362.
- Obesity Action Coalition. Person-First Language for Obesity. 2017. Available at http://www.obesityaction.org/weight-bias-and-stigma/people-first-language-for-obesity, Accessed 19 September 2017.
- 11. National Alliance on Mental Illness. How to Be Inclusive and Welcoming. 2017. Available at https://www.nami.org/Get-Involved/NAMI-FaithNet/How-to-Be-Inclusive-and-Welcoming, Accessed 19 September 2017.
- Psychiatric Rehabilitation Association. PRA Language Guidelines. 2002. Available at https://www.nccdp.org/resources/PRAlanguageguidelines.pdf, Accessed 6 September 2017.
- 13. Canadian Alzheimer's Society. Person-Centered Language. December 2012. Available at http://www.alzheimer.ca/~/media/Files/national/Culture-change/culture-person-centred-language-2012_e.pdf, Accessed 6 September 2017.
- 14. Kapitan, A. On "Person-First Language": It's Time To Actually Put The Person First. RadicalCopyEditor.com. 3 July 2017. Available at https://radicalcopyeditor.com/2017/07/03/person-centered-language/, Accessed 6 September 2017.
- 15. Collier, R. Person-first language: Noble intent but to what effect? CMAJ. 2012 Dec 11; 184(18): 1977-1978.
- 16. Mackelprang, R. Cultural Competence in Persons with Disabilities. In: Lum, Doman, Ed. Culturally Competent Practice. A framework for understanding diverse groups and justice issues. 4th ed. Belmont, CA: Brooks/Cole CENGAGE Learning; 2011: 437-465.

AMA Manual of Style > Section 2 Style > Subsection 11 Correct and Preferred Usage > 11.10 Inclusive Language > 11.10.4 Disabilities:

According to the Americans with Disabilities Act (http://www.usdoj.gov/crt/ada/), "a disability exists when an individual has any physical or psychological illness that 'substantially limits' a major life activity, such as walking, learning, breathing, working, or participating in community activities.'

Avoid labeling (and thus equating) people with their disabilities or diseases (eg, the blind, schizophrenics, epileptics). Instead, put the person first. Avoid describing persons as victims or with other emotional terms that suggest helplessness (afflicted with, suffering from, stricken with, maimed). Avoid euphemistic descriptors such as physically challenged or special. Avoid metaphors that may be inappropriate and insensitive (blind to the truth, deaf to the request). For similar reasons, some publications avoid the term double-blind when referring to a study's methodology.

Note: Some manuscripts use certain phrases many times, and changing, for example, "AIDS patients" to "persons with AIDS" at every occurrence may result in awkward and stilted text. In such cases, the adjectival form may be used.

Resolution: 006 (A-19)

Page 3 of 3

RELEVANT AMA POLICY

Person-First Language for Obesity H-440.821

Our AMA: (1) encourages the use of person-first language (patients with obesity, patients affected by obesity) in all discussions, resolutions and reports regarding obesity; (2) encourages the use of preferred terms in discussions, resolutions and reports regarding patients affected by obesity including weight and unhealthy weight, and discourage the use of stigmatizing terms including obese, morbidly obese, and fat; and (3) will educate health care providers on the importance of person-first language for treating patients with obesity; equipping their health care facilities with proper sized furniture, medical equipment and gowns for patients with obesity; and having patients weighed respectfully.

(Policy Timeline: Res. 402, A-17 Modified: Speakers Rep., I-17)

Resolution: 007

(A-19)

Introduced by: Resident and Fellow Section

Subject: Delegation of Informed Consent

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, The process of witnessed informed consent is a vital prerequisite to any invasive procedure or treatment, and constitutes a detailed back-and-forth discussion between the healthcare team and the patient regarding specific risks, benefits, indications and alternatives of that particular procedure or treatment; and

Whereas, Many physician groups and departments of physicians (particularly, specialists and subspecialists) frequently work as a well-organized "team" in order to better care for the patient and to improve the efficiency of patient care; and

Whereas, Allowing other qualified members of the health care team to participate in the informed care process may provide the patient with more information, more opportunities to ask questions and, ultimately, to be able to make an informed decision; and

Whereas, There are many situations when it is impractical to prohibit other competent members of the health care team (residents, nurses, physician assistants) to participate in the informed consent process; and

Whereas, The process of obtaining informed consent is a vital component in residency training to produce a competent independent physician; and

Whereas, A 2017 Pennsylvania Supreme Court ruling (*Shinal v. Toms*) mandated that a physician may not delegate to others his or her obligation to provide sufficient information to obtain a patient's informed consent¹; and

Whereas, The Pennsylvania Supreme Court further stated in its judgment that the duty of informed consent is a non-delegable duty owed by the physician conducting the surgery or treatment; and

Whereas, This legal ruling may lead to a precedent with potential devastating and adverse unintended consequences to patient health by causing unnecessary and potentially harmful delays across the country; therefore be it

RESOLVED, That our American Medical Association in cooperation with other relevant stakeholders advocate that a qualified physician be able to delegate his or her duty to obtain informed consent to another provider that has knowledge of the patient, the patient's condition, and the procedures to be performed on the patient (Directive to Take Action); and be it further

Resolution: 007 (A-19)

Page 2 of 3

1 RESOLVED, That our AMA study the implications of the Shinal v. Toms ruling and its potential

2 effects on the informed consent process. (Directive to Take Action)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 05/01/19

References:

1. Shinal v. Toms, 2017 WL 2655387, at *17 (Pa. June 20, 2017).

RELEVANT AMA POLICY

2.1.1 Informed Consent

Informed consent to medical treatment is fundamental in both ethics and law. Patients have the right to receive information and ask questions about recommended treatments so that they can make well-considered decisions about care. Successful communication in the patient-physician relationship fosters trust and supports shared decision making.

The process of informed consent occurs when communication between a patient and physician results in the patients authorization or agreement to undergo a specific medical intervention. In seeking a patients informed consent (or the consent of the patients surrogate if the patient lacks decision-making capacity or declines to participate in making decisions), physicians should:

- (a) Assess the patients ability to understand relevant medical information and the implications of treatment alternatives and to make an independent, voluntary decision.
- (b) Present relevant information accurately and sensitively, in keeping with the patients preferences for receiving medical information. The physician should include information about:
- (i) the diagnosis (when known);
- (ii) the nature and purpose of recommended interventions;
- (iii) the burdens, risks, and expected benefits of all options, including forgoing treatment.
- (c) Document the informed consent conversation and the patients (or surrogates) decision in the medical record in some manner. When the patient/surrogate has provided specific written consent, the consent form should be included in the record.

In emergencies, when a decision must be made urgently, the patient is not able to participate in decision making, and the patients surrogate is not available, physicians may initiate treatment without prior informed consent. In such situations, the physician should inform the patient/surrogate at the earliest opportunity and obtain consent for ongoing treatment in keeping with these guidelines.

AMA Principles of Medical Ethics: I,II,V,VIII

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

AMA Opposition to "Procedure-Specific" Informed Consent H-320.951

Our AMA opposes legislative measures that would impose procedure-specific requirements for informed consent or a waiting period for any legal medical procedure.

Citation: (Res. 226, A-99; Reaffirmed: Res. 703, A-00; Reaffirmed: BOT Rep. 6, A-10

Informed Consent and Decision-Making in Health Care H-140.989

- (1) Health care professionals should inform patients or their surrogates of their clinical impression or diagnosis; alternative treatments and consequences of treatments, including the consequence of no treatment; and recommendations for treatment. Full disclosure is appropriate in all cases, except in rare situations in which such information would, in the opinion of the health care professional, cause serious harm to the patient.
- (2) Individuals should, at their own option, provide instructions regarding their wishes in the event of their incapacity. Individuals may also wish to designate a surrogate decision-maker. When a patient is incapable of making health care decisions, such decisions should be made by a surrogate acting pursuant to the previously expressed wishes of the patient, and when such wishes are not known or ascertainable, the surrogate should act in the best interests of the patient.
- (3) A patient's health record should include sufficient information for another health care professional to

Resolution: 007 (A-19)

Page 3 of 3

assess previous treatment, to ensure continuity of care, and to avoid unnecessary or inappropriate tests or therapy.

- (4) Conflicts between a patient's right to privacy and a third party's need to know should be resolved in favor of patient privacy, except where that would result in serious health hazard or harm to the patient or others.
- (5) Holders of health record information should be held responsible for reasonable security measures through their respective licensing laws. Third parties that are granted access to patient health care information should be held responsible for reasonable security measures and should be subject to sanctions when confidentiality is breached.
- (6) A patient should have access to the information in his or her health record, except for that information which, in the opinion of the health care professional, would cause harm to the patient or to other people.
- (7) Disclosures of health information about a patient to a third party may only be made upon consent by the patient or the patient's lawfully authorized nominee, except in those cases in which the third party has a legal or predetermined right to gain access to such information.

Citation: BOT Rep. NN, A-87; Reaffirmed: Sunset Report, I-97; Reaffirmed: Res. 408, A-02; Reaffirmed: BOT Rep. 19, I-06; Reaffirmation A-07; Reaffirmation A-09; Reaffirmed: BOT Rep. 05, I-16

Resolution: 008

(A-19)

Introduced by: Minority Affairs Section

7

8

9

11 12 13

14 15 16

17

18 19

20

21

22 23

24

252627

28

29

30 31

32

33

34 35

36

GLMA: Health Professionals Advancing LGBTQ Equality

Subject: Preventing Anti-Transgender Violence

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, A recent event has increased attention on violent crimes reported by the Lesbian,
Gay, Bisexual, Transgender, and Questioning (LGBTQ) or gender non-conforming communities
yet most media outlets have failed to accurately educate the public regarding the reality of the
discrimination and physical dangers faced by members of the LGBTQ community, 1-7 especially

5 Black transgender people and other transgender people of color; and 6

Whereas, Transgender individuals are people whose gender identity or gender expression differs from their sex assigned at birth;⁸ and

Whereas, Transgender people who are People of Color, disabled, female identified, or a member of another oppressed group may struggle with discrimination on multiple levels;^{9,10} and

Whereas, Violence against transgender people is often underreported due to transphobia and mistrust of law enforcement;¹¹ and

Whereas, In 2013, the Human Rights Campaign published its first report that tracked fatal violence against transgender people in the US and published its most recent report in 2018; and

Whereas, In the past six years of reporting by the Human Rights Campaign, 80% of all known transgender homicide victims were transgender women of color, 69% were Black transgender women; and

Whereas, Since 2013, at least 128 transgender women, transgender men, and non-binary people (people whose gender is not male or female) have been killed across 32 states and 87 cities in the US:¹¹ and

Whereas, In 2017, there were 29 homicides of transgender people in the US reported in the media, the highest number ever recorded, in addition to many more that were not publicly known; and

Whereas, In 2018, advocates tracked at least 226 deaths of transgender people in the US due to fatal violence, 82% of whom were transgender women of color and 73% of whom were Black transgender women;¹¹ and

Whereas, In the summer of 2018, violent attacks claimed the lives of nine Black transgender women in the span of only 10 weeks; and

Resolution: 008 (A-19) Page 2 of 3

Whereas, The Federal Bureau of Investigation reported a 17% increase in hate crime reports in 2017 compared to 2016 data, a rise for the third consecutive year: 12 and

2 3 4

1

Whereas, Of the more than 7,100 hate crimes reported in 2017, the Federal Bureau of Investigation concluded nearly three out of five were motivated by race and ethnicity; and

5 6 7

8

Whereas, Numerous studies have found that transgender people, especially transgender people of color, face high rates of sexual assault, intimate partner violence, and other non-fatal violence: and

9 10 11

12

13

14

Whereas, The largest survey to date of transgender individuals in the United States, the 2015 US Transgender Survey, found that 13% of all respondents reported being physically assaulted in the previous year; 47% reported ever experiencing sexual assault, including 10% in the previous year; and 35% reported ever experiencing physical violence from an intimate partner;¹³ and

15 16 17

18

Whereas, The physical risks faced by transgender individuals can have long and short-term negative impacts on the physical and mental health of these individuals, survivors, their communities, and the nation as a whole; therefore be it

19 20 21

22

23

24

RESOLVED, That our American Medical Association partner with other medical organizations and stakeholders to immediately increase efforts to educate the general public, legislators, and members of law enforcement using verified data related to the hate crimes against transgender individuals highlighting the disproportionate number of Black transgender women who have succumbed to violent deaths (Directive to Take Action); and be it further

25 26 27

28

29

30

31

32

RESOLVED, That our AMA advocate for federal, state, and local law enforcement agencies to consistently collect and report data on hate crimes, including victim demographics, to the FBI; for the federal government to provide incentives for such reporting; and for demographic data on an individual's birth sex and gender identity be incorporated into the National Crime Victimization Survey and the National Violent Death Reporting System, in order to quickly identify positive and negative trends so resources may be appropriately disseminated (Directive to Take Action); and be it further

33 34 35

36

37

RESOLVED, That our AMA advocate for a central law enforcement database to collect data about reported hate crimes that correctly identifies an individual's birth sex and gender identity, in order to quickly identify positive and negative trends so resources may be appropriately disseminated (Directive to Take Action); and be it further

38 39 40

41

RESOLVED. That our AMA advocate for stronger law enforcement policies regarding interactions with transgender individuals to prevent bias and mistreatment and increase community trust (Directive to Take Action); and be it further

42 43 44

45

RESOLVED, That our AMA advocate for local, state, and federal efforts that will increase access to mental health treatment and that will develop models designed to address the health disparities that LGBTQ individuals experience (Directive to Take Action); and be it further

46 47 48

49

50

RESOLVED. That our AMA issue a press release following the conclusion of the annual House of Delegates meeting with updates to be published in both scientific and mainstream publications regarding the prevalence of physical and mental health conditions and barriers

51 faced by the LGBTQ community. (Directive to Take Action)

Page 3 of 3

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 05/09/19

References:

- 1. Ramirez JL, Gonzalez KA, Galupo MP. "Invisible During My Own Crisis": Responses of LGBT People of Color to the Orlando Shooting. J Homosex 2018;65:579-99.
- 2. Schneeberger AR, Dieti MF, Muenzenmaier KH, Huber CG, Lang UE. Stressful childhood experiences and health outcomes in sexual minority populations: a systematic review. Soc Psychiatry Psychiatr Epidemiol 2014;49:1427-45.
- 3. Hightow-Weidman LB, Phillips G, 2nd, Jones KC, et al. Racial and sexual identity-related maltreatment among minority YMSM: prevalence, perceptions, and the association with emotional distress. AIDS Patient Care STDS 2011;25 Suppl 1:S39-45.
- 4. Brumbaugh-Johnson SM, Hull KE. Coming Out as Transgender: Navigating the Social Implications of a Transgender Identity. J Homosex 2018:1-30.
- 5. Rood BA, Reisner SL, Surace FI, Puckett JA, Maroney MR, Pantalone DW. Expecting Rejection: Understanding the Minority Stress Experiences of Transgender and Gender-Nonconforming Individuals. Transgend Health 2016;1:151-64.
- 6. Winter S, Diamond M, Green J, et al. Transgender people: health at the margins of society. Lancet 2016.
- 7. Schuster MA, Reisner SL, Onorato SE. Beyond Bathrooms--Meeting the Health Needs of Transgender People. N Engl J Med 2016:375:101-3
- 8. The Joint Commission. Advancing Effective Communication, Cultureal Competence, and Patient- and Famly-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community: A Field Guide. Oak Brook, IL: The Joint Commission; 2011.
- 9. Green ER, Maurer, L.M., The teaching Transgender Toolkit: A facilitator's guide to increasing knowledge, decreasing prejudice & building skills. Ithaca NY: Planned Parenthood of the Southern Finger Lakes: Out for Health; 2015.
- 10. Crenshaw K. Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. Stanford Law Review 1991;43:1241-99.
- 11. Human Rights Campaign. A National Epidemic: Fatal Anti-Transgender Violence in America in 2018. 2019.
- 12. Hate Crimes. 2019. at https://www.fbi.gov/investigate/civil-rights/hate-crimes.
- 13. James SE, Herman JL, Rankin S, Keisling M, Mottet L, Anafi, M. The Report of the 2015 U.S. Transgender Survey. 2016.

Resolution: 009

(A-19)

Introduced by: Minority Affairs Section

Subject: References to Terms and Language in Policies Adopted to Protect

Populations from Discrimination and Harassment

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, The concept of protection against discrimination or harassment is not controversial, however, generally accepted, standard language for protected classes or groups does not exist among national organizations; and

3 4 5

1

2

Whereas, American Medical Association policy (and therefore Policy Finder) has multiple, inconsistent references with variable language regarding protection against discrimination or harassment against populations; therefore be it

7 8 9

6

RESOLVED, That our American Medical Association undertake a study to identify all discrimination and harassment references in AMA policies and the code of ethics, noting when the language is consistent and when it is not (Directive to Take Action); and be it further

11 12 13

14

10

RESOLVED, That our AMA research language and terms used by other national organizations and the federal government in their policies on discrimination and harassment (Directive to Take Action); and be it further

15 16 17

18 19 RESOLVED, That our AMA present the preliminary study results the Minority Affairs Section, the Women's Physician Section, and the Advisory Committee on LGBTQ Issues to reach consensus on optimal language to protect vulnerable populations including racial and ethnic minorities, sexual and gender minorities, and women, from discrimination and harassment (Directive to Take Action); and be it further

21 22 23

24

20

RESOLVED, That our American Medical Association produce a report within 18 months with study results and recommendations. (Directive to Take Action)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 05/09/19

Resolution: 010

(A-19)

Introduced by: **New Mexico**

Subject: Covenants Not to Compete

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Covenants not to compete have been used to force physicians to leave communities if they leave hospital employment; and

2 3 4

Whereas, Recruiting and promoting new partners, building their referral bases, and purchasing necessary equipment is a significantly expensive undertaking; and

5 6 7

Whereas, Practices endure significant financial harm when a hospital can lure a partner away, and a requirement to pay liquidated damages when that happens mitigates the financial harm without requiring the partner to leave the community; and

9 10 11

12

8

Whereas, New Mexico passed a statue that prohibits covenants not to compete for employed physicians but allows for liquidated damages to be paid when a partner who is a part owner in a practice is lured away by a competing hospital system; and

13 14 15

Whereas, The New Mexico statute is a model that could be used by the AMA Council on Legislation as an example for other states; and

16 17 18

Whereas, The AMA Council on Ethical and Judicial Affairs opposes covenants not to compete in all circumstances: therefore be it

19 20 21

22

23

RESOLVED, That our American Medical Association consider as the basis for model legislation the New Mexico statute allowing a requirement that liquidated damages be paid when a physician partner who is a part owner in practice is lured away by a competing hospital system (Directive to Take Action); and be it further

24 25 26

27

28

29

30

RESOLVED, That our AMA ask our Council on Ethical and Judicial Affairs to reconsider their blanket opposition to covenants not to compete in the case of a physician partner who is a part owner of a practice, in light of the protection that liquidated damages can confer to independent physician owned partnerships, and because a requirement to pay liquidated damages does not preclude a physician from continuing to practice in his or her community. (Directive to Take Action)

31

Fiscal Note: Minimal - less than \$1,000.

Received: 05/09/19

Resolution: 011

(A-19)

Introduced by: Michigan

Subject: Mature Minor Consent to Vaccinations

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Vaccines have been one of the most effective methods of infectious disease control in the past century, preventing 732,000 premature deaths in children born in the United States between 1994 and 2013; and

Whereas, One of the goals of Healthy People 2020 is to increase immunization rates, targeting a reduction in the incidence of 17 vaccine-preventable diseases in the United States; and

Whereas, There have been several recent well-publicized outbreaks of vaccine-preventable illnesses such as measles, mumps, and pertussis in the United States, including the 2018 Michigan measles outbreak; and

Whereas, The prevalence of unvaccinated pediatric patients is rising in the United States, and many children are unvaccinated due to parental distrust of vaccines; and

Whereas, Despite legislative efforts to regulate opt-out waivers for vaccinations, the Michigan immunization waiver rate remains higher than three percent for both kindergarten and eighth grade students, with greater than 70 percent of those waivers for philosophical rather than religious or medical reasons; and

Whereas, A 2018 study found that three of the nation's 14 metropolitan "hotspots" for non-medical exemption from vaccination are located in Michigan--Troy, Warren, and Detroit-demonstrating a high risk of vaccine-preventable disease outbreaks; and

Whereas, Declining vaccination rates increase the probability of outbreaks of vaccinepreventable diseases, and states with more opportunities for vaccination exemption have more measles outbreaks; and

Whereas, Unvaccinated adolescents report interest in receiving vaccines to prevent against common childhood illnesses; and

Whereas, Federal law does not require parental consent for vaccinations and many states, including Michigan, do not have comprehensive statutes surrounding vaccination policy; and

Whereas, Minors in the majority of states, including Michigan, are able to consent to some mental health services, sexually transmitted disease testing and treatment, birth control, and pregnancy related care; and

Resolution: 011 (A-19) Page 2 of 5

Whereas, Adolescents in 21 states do not require parental consent for treatment of reportable 1 2 diseases, which include hepatitis B, measles, mumps, and pertussis; and

3 4

Whereas, The inability for minors to provide consent to vaccinations has been cited as a barrier to vaccination rates; and

5 6 7

8

9

Whereas, An American Academy of Pediatrics' article proposed minor consent to vaccination via the mature minor doctrine, a widely accepted legal concept allowing "certain older minors who have the capacity to give informed consent to do so for care that is within the mainstream of medical practice, not high risk, and provided in a non-negligent manner;" and

10 11 12

Whereas, Vaccinations are safe, effective, low-risk, and necessary for a multi-faceted, comprehensive approach to public health and it is thus in the interest of the medical community and concerned citizens to promote access to vaccination; and

14 15 16

17

18

13

Whereas, Allowing mature minors an avenue to provide for their own personal health, when they have no medical contraindications to the vaccinations and are given the same comprehensive vaccine information as consenting adults, abides by the same ethical standards as other procedures allowed for in Michigan without parental consent; therefore be it

19 20 21

RESOLVED, That our American Medical Association amend the policy H-440.830, "Education and Public Awareness on Vaccine Safety and Efficacy," by addition and deletion as follows:

22 23 24

25

26

27

28

29

30

31

32

33

34

35

36

37

38

39

40

41

42

43

Our AMA (a) encourages the development and dissemination of evidence-based public awareness campaigns aimed at increasing vaccination rates; (b) encourages the development of educational materials that can be distributed to patients and their families clearly articulating the benefits of immunizations and highlighting the exemplary safety record of vaccines; (c) supports the development and evaluation, in collaboration with health care providers, of evidence-based educational resources to assist parents in educating and encouraging other parents who may be reluctant to vaccinate their children; (d) encourages physicians and state and local medical associations to work with public health officials to inform those who object to immunizations about the benefits of vaccinations and the risks to their own health and that of the general public if they refuse to accept them; (e) will promote the safety and efficacy of vaccines while rejecting claims that have no foundation in science; and (f) supports state policies allowing adolescents to provide their own consent for vaccination and encourages state legislatures to establish comprehensive vaccine and minor consent policies; and (g) will continue its ongoing efforts with other immunization advocacy organizations to assist physicians and other health care professionals in effectively communicating to patients, parents, policy makers, and the media that vaccines do not cause autism and that decreasing immunization rates have resulted in a resurgence of vaccine-preventable diseases and deaths. (Modify Current HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/09/19

Page 3 of 5

References:

- "Vaccination greatly reduces disease, disability, death and inequity worldwide." World Health Organization, 2008. https://www.who.int/bulletin/volumes/86/2/07-040089/en/. Accessed February 6, 2019.
- "Benefits from Immunization During the Vaccines for Children Program Era" United States, 1994-2013." Centers for Disease Control and Prevention, 2014. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6316a4.htm. Accessed February 6, 2019.
- 3. "Immunization and Infectious Diseases." Office of Disease Prevention and Health Promotion.
- https://www.healthypeople.gov/2020/topics-objectives/topic/immunization-and-infectious-diseases. Accessed February 6, 2019.
- 4. "Michigan measles cases reach 15; health officials urge protection through vaccination." Michigan Department of Health and Human Services, 2018. https://www.michigan.gov/mdhhs/0,5885,7-339--482832--,00.html. Accessed February 6, 2019.
- Measles Cases and Outbreaks. Centers for Disease Control and Prevention. https://www.cdc.gov/measles/casesoutbreaks.html. Published February 18, 2019. Accessed February 25, 2019.
- Mumps Cases and Outbreaks. Centers for Disease Control and Prevention. https://www.cdc.gov/mumps/outbreaks.html. Accessed February 25, 2019.
- Morbidity and Mortality Weekly Report (MMWR). Centers for Disease Control and Prevention. https://www.cdc.gov/mmwr/volumes/67/wr/mm6740a4.htm. Published October 11, 2018. Accessed February 25, 2019.
- 8. Freed, G. L., Clark, S. J., Butchart, A. T., Singer, D. C., & Davis, M. M. (2010). Parental vaccine safety concerns in 2009. Pediatrics. 125(4). 654-659.
- 9. Brown, K. F., Kroll, J. S., Hudson, M. J., Ramsay, M., Green, J., Long, S. J., ... & Sevdalis, N. (2010). Factors underlying parental decisions about combination childhood vaccinations including MMR: a systematic review. Vaccine, 28(26), 4235-4248.
- "Immunization Status of School Children in Michigan." Michigan Department of Health and Human Services, 2017. https://www.michigan.gov/documents/mdch/School_Summary_2014_483316_7.pdf. Accessed February 6, 2019.
- 11. Ford CA, Skiles MP, English A, et al. "Minor consent and delivery of adolescent vaccines." J Adolesc Health. 2013;54(2):183-9. doi: 10.1016/j.jadohealth.2013.07.028
- 12. "What Would Happen If We Stopped Vaccinations?" Centers for Disease Control and Prevention, 2017. https://www.cdc.gov/vaccines/vac-gen/whatifstop.htm. Accessed February 6, 2019.
- 13. Whittington MD, Kempe A, Dempsey A, Herlihy R, Campbell JD. Impact of Nonmedical Vaccine Exemption Policies on the Health and Economic Burden of Measles. Academic Pediatrics. 2017;17(5):571-576.
- 14. Gander, Kashmira. "Measles Outbreak: Children of Anti-Vaxxers Are Asking How to Get Vaccinated Without Their Parents Knowing." Newsweek, February 1, 2019. https://www.newsweek.com/measles-outbreak-children-anti-vaxxers-asking-how-get-vaccinated-without-1314428. Accessed February 6, 2019.
- 15. Woodruff BA, Unti L, Coyle K, Boyer-Chuanroong L. Parents' attitudes toward school-based hepatitis B vaccination of their children. Pediatrics. 1996;98:410-413
- 16. English A, Kenney K. State Minor Consent Laws: A Summary, Third Edition. Center for Adolescent Health and the Law. https://www.cahl.org/state-minor-consent-laws-a-summary-third-edition/. Published 2003. Accessed February 28, 2019.
- 17. English A, Shaw FE, Mccauley MM, Fishbein DB. Legal Basis of Consent for Health Care and Vaccination for Adolescents. Pediatrics. 2008;121(Supplement 1). doi:10.1542/peds.2007-1115j.
- 18. Ford CA, Skiles MP, English A, et al. "Minor consent and delivery of adolescent vaccines." J Adolesc Health. 2013;54(2):183-9. doi: 10.1016/j.jadohealth.2013.07.028
- 19. Ford CA, English A, Davenport AF et al. "Increasing adolescent vaccination: barriers and strategies in the context of policy, legal, and financial issues." J Adolesc Health. 2009;44:568-74. doi: 10.1016/j.jadohealth.2008.11.015

RELEVANT AMA POLICY

Education and Public Awareness on Vaccine Safety and Efficacy H-440.830

- 1. Our AMA (a) encourages the development and dissemination of evidence-based public awareness campaigns aimed at increasing vaccination rates; (b) encourages the development of educational materials that can be distributed to patients and their families clearly articulating the benefits of immunizations and highlighting the exemplary safety record of vaccines; (c) supports the development and evaluation, in collaboration with health care providers, of evidence-based educational resources to assist parents in educating and encouraging other parents who may be reluctant to vaccinate their children; (d) encourages physicians and state and local medical associations to work with public health officials to inform those who object to immunizations about the benefits of vaccinations and the risks to their own health and that of the general public if they refuse to accept them; (e) will promote the safety and efficacy of vaccines while rejecting claims that have no foundation in science; and (f) will continue its ongoing efforts with other immunization advocacy organizations to assist physicians and other health care professionals in effectively communicating to patients, parents, policy makers, and the media that vaccines do not cause autism and that decreasing immunization rates have resulted in a resurgence of vaccine-preventable diseases and deaths.
- 2.Our AMA: (a) supports the rigorous scientific process of the Advisory Committee on Immunization Practices as well as its development of recommended immunization schedules for the nation; (b) recognizes the substantial body of scientific evidence that has disproven a link

Page 4 of 5

between vaccines and autism; and (c) opposes the creation of a new federal commission on vaccine safety whose task is to study an association between autism and vaccines. Citation: Res. 9, A-15; Modified: CSAPH Rep. 1, I-15; Appended: Res. 411, A-17

Achieving National Adolescent Immunization Goals H-440.901

Our AMA: (1) endorses the National Adolescent Vaccine Coverage Goals; and (2) endorses the collaboration of physicians, public health officials and legislators in each state to carry out strategies that ensure the National Adolescent Vaccine Coverage Goals are met. Citation: Res. 411, I-98; Modified and Reaffirmed: CSAPH Rep. 2, A-08; Reaffirmed: CSAPH Rep. 01, A-18

Childhood Immunizations H-60.969

- 1. Our AMA will lobby Congress to provide both the resources and the programs necessary, using the recommendations of the National Vaccine Advisory Committee and in accordance with the provision set forth in the National Vaccine Injury Compensation Act, to ensure that children nationwide are immunized on schedule, thus representing progress in preventive medicine.
- 2. Our AMA endorses the recommendations on adolescent immunizations developed by the Advisory Committee for Immunization Practices and approved by both the American Academy of Family Physicians and the American Academy of Pediatrics.
- 3. Our AMA will develop model state legislation to require that students entering middle or junior high school be adequately immunized according to current national standards.
- 4. Our AMA encourages state medical societies to advocate legislation or regulations in their state that are consistent with the AMA model state legislation.
- 5. Our AMA will continue to work with managed care groups and state and specialty medical societies to support a dedicated preventive health care visit at 11-12 years of age.
- 6. Our AMA will work with the American Academy of Family Physicians and the American Academy of Pediatrics to strongly encourage the Centers for Medicare & Medicaid Services to deactivate coding edits that cause a decrease in immunization rates for children, and to make these edit deactivations retroactive to January 1, 2013.

Citation: (Res. 542, A-92; CSA Rep. 4, I-95; Reaffirmed by BOT Rep. 24, A-97; Reaffirmation A-05; Appended: Res. 121, A-13

Confidential Health Services for Adolescents H-60.965Our AMA:

- (1) reaffirms that confidential care for adolescents is critical to improving their health;
- (2) encourages physicians to allow emancipated and mature minors to give informed consent for medical, psychiatric, and surgical care without parental consent and notification, in conformity with state and federal law;
- (3) encourages physicians to involve parents in the medical care of the adolescent patient, when it would be in the best interest of the adolescent. When, in the opinion of the physician, parental involvement would not be beneficial, parental consent or notification should not be a barrier to care:
- (4) urges physicians to discuss their policies about confidentiality with parents and the adolescent patient, as well as conditions under which confidentiality would be abrogated. This discussion should include possible arrangements for the adolescent to have independent access to health care (including financial arrangements);
- (5) encourages physicians to offer adolescents an opportunity for examination and counseling apart from parents. The same confidentiality will be preserved between the adolescent patient and physician as between the parent (or responsible adult) and the physician:
- (6) encourages state and county medical societies to become aware of the nature and effect of laws and regulations regarding confidential health services for adolescents in their respective

Page 5 of 5

jurisdictions. State medical societies should provide this information to physicians to clarify services that may be legally provided on a confidential basis;

- (7) urges undergraduate and graduate medical education programs and continuing education programs to inform physicians about issues surrounding minors' consent and confidential care, including relevant law and implementation into practice;
- (8) encourages health care payers to develop a method of listing of services which preserves confidentiality for adolescents; and
- (9) encourages medical societies to evaluate laws on consent and confidential care for adolescents and to help eliminate laws which restrict the availability of confidential care. Citation: (CSA Rep. A, A-92; Reaffirmed by BOT Rep. 24, A-97; Reaffirmed by BOT Rep. 9, A-98; Reaffirmed: Res. 825, I-04; Reaffirmation A-08; Reaffirmed: CMS Rep. 2, I-14

Resolution: 012 (A-19)

Introduced by: Medical Student Section

Subject: Improving Body Donation Regulation

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Body donation is essential to medical-surgical education, continuing education programs, clinical practice, and research, even as new virtual technology emerges¹⁻¹⁷; and

Whereas, Research and education conducted on donated bodies is beneficial to patients, society, and the medical profession^{14,17,18,19,20,21}; and

Whereas, Body donation, transplant tissue donation, and vascular organ donation are all examples of how an individual person may donate part or all of his or her body to the institutions of science and medicine^{22,23,24}; and

Whereas, Transplant tissue and vascular organ donations are heavily regulated on a federal level by the Food and Drug Administration (FDA) and the Health Resources Service Administration (HRSA), respectively^{25,26,27}; and

Whereas, Body donation is classified as neither transplant tissue donation nor vascular organ donation and is thus not regulated by either the FDA or HRSA, creating a gap in federal oversight and resulting in state- and institutional-level regulation^{16,29,30}; and

Whereas, As a result, body donation practices lack transparency and consistency, creating loopholes between federal, state, and institutional policy^{16,29,30,31,32}; and

Whereas, The lack of consistent and appropriate monitoring of bodies and body parts results in lost tissues and incorrectly returned remains^{30,33}; and

Whereas, Lack of regulation allows for market incentives to drive unethical body part acquisitions, requiring each individual institution, research team, and health care provider to set their own ethical bar^{30,31,32}; and

Whereas, Lack of regulation allows misleading marketing that focuses on financial incentives (e.g., free cremation) and does not clearly explain how donated bodies are used, which leads to an incongruence between donor/family wishes and understanding, and the resulting use of their bodies^{29,32,34}; and

Whereas, The AMA supports federal oversight for processes involving tissue and organ donation to the medical profession through existing Policy (H-370.988); and

Whereas, The AMA Code of Ethics has established importance of removing potential financial incentives for organ donation (6.1.3), but there are no analogous policies for body donation; and

Page 2 of 4

1 Whereas, Multiple institutional and professional organizational guidelines for ethical and 2

productive body donation programs exist that could inform federal regulation³⁶; therefore be it

3

- 4 RESOLVED, That our American Medical Association recognize the need for ethical,
- 5 transparent, and consistent body donation regulations. (New HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/09/19

- Papa V, Vaccarezza M. Teaching Anatomy in the XXI Century: New Aspects and Pitfalls," The Scientific World Journal, vol. 2013, Article ID 310348, 5 pages, 2013. https://doi.org/10.1155/2013/310348.
- Older, J., Anatomy: a must for teaching the next generation. Surgeon, 2004. 2(2): p. 79-90. 2.
- Ghosh, S.K., Cadaveric dissection as an educational tool for anatomical sciences in the 21st century. Anat Sci Educ, 2017. 10(3): p. 286-299.
- Estai, M. and S. Bunt, Best teaching practices in anatomy education: A critical review. Ann Anat, 2016. 208: p. 151-157.
- Sugand, K., P. Abrahams, and A. Khurana, The anatomy of anatomy: a review for its modernization. Anat Sci Educ, 2010. 3(2): p. 83-93
- Bin P, Delbon P, Piras M, Paternoster M, Di Lorenzo P, Conti A. Donation of the body for scientific purposes in Italy: ethical and medico-legal considerations. Open Medicine. 2016;11(1):316-320. doi:10.1515/med-2016-0060.
- 7. Jansen, S., et al., Fresh frozen cadaver workshops for advanced vascular surgical training. ANZ J Surg, 2014. 84(11): p. 877-
- Sharma, M., et al., Construct validity of fresh frozen human cadaver as a training model in minimal access surgery. Jsls, 2012. 16(3): p. 345-52.
- Wise, E.M., et al., The impact of a cadaver-based airway lab on critical care fellows' direct laryngoscopy skills. Anaesth Intensive Care, 2015. 43(2): p. 224-9.
- 10. Willaert W, Tozzi F, Herzeele IV, D'Herde K, Pattyn P. Systematic review of surgical training on reperfused human cadavers. Acta Chirurgica Belgica. 2018;118(3):141-151. doi:10.1080/00015458.2017.1407099.
- 11. Calio BP, Kepler CK, Koerner JD, Rihn JA, Millhouse P, Radcliff KE. Outcome of a Resident Spine Surgical Skills Training Program. Clinical Spine Surgery. 2017;30(8). doi:10.1097/bsd.0000000000000111.
- 12. Lin Y, Mukhopadhyay S, Meguid RA, Kuwayama DP. The Colorado Humanitarian Surgical Skills Workshop: A Cadaver-Based Workshop to Prepare Residents for Surgery in Austere Settings. Journal of Surgical Education. 2018;75(2):383-391. doi:10.1016/j.jsurg.2017.08.009.
- 13. Minneti M, Baker CJ, Sullivan ME. The Development of a Novel Perfused Cadaver Model With Dynamic Vital Sign Regulation and Real-World Scenarios to Teach Surgical Skills and Error Management. Journal of Surgical Education. 2018;75(3):820-827. doi:10.1016/j.jsurg.2017.09.020.
- 14. Schulz C. The Value of Clinical Practice in Cadaveric Dissection: Lessons Learned From a Course in Eye and Orbital Anatomy. Journal of Surgical Education. 2017;74(2):333-340. doi:10.1016/j.jsurg.2016.09.010.
- 15. Culliford E. The Body Trade: Cadavers in the ballroom: Doctors practice their craft at U.S. hotels. Reuters. https://www.reuters.com/investigates/special-report/usa-bodies-hotels/. Published December 15, 2017.
- 16. Anteby M. Markets, Morals, and Practices of Trade: Jurisdictional Disputes in the U.S. Commerce in Cadavers. Administrative Science Quarterly, 2010;55(4):606-638, doi:10.2189/asgu.2010.55.4.606.
- 17. Ghazanfar H, Rashid S, Hussain A, Ghazanfar M, Ghazanfar A, Javaid A. Cadaveric Dissection a Thing of the Past? The Insight of Consultants, Fellows, and Residents. Muacevic A, Adler JR, eds. Cureus. 2018;10(4):e2418. doi:10.7759/cureus.2418.
- 18. Rehkämper G. Human Dissection in Medical Education: More than Just Anatomy, GMS Journal for Medical Education. 2016;33(5):Doc68.doi:10.3205/zma001067
- 19. Brenner, Erich & Maurer, H & Moriggl, Bernhard. (2003). The human cadaver as an educational tool classification and comparison with other educational tools. Ann Anat. 185. 229-230.
- 20. Older J. Anatomy: A must for teaching the next generation. The Surgeon. 2004;2(2):79-90. doi:10.1016/s1479-666x(04)80050-
- 21. Pais D, Casal D, Mascarenhas-Lemos L, Barata P, Moxham BJ, Goyri-Oneill J. Outcomes and satisfaction of two optional cadaveric dissection courses: A 3-year prospective study. Anatomical Sciences Education. 2016;10(2):127-136. doi:10.1002/ase.1638.
- 22. Boulware LE, Ratner LE, Cooper LA, LaVeist TA, Powe NR. Whole body donation for medical science: a population-based study.Clin Anat. 2004 Oct; 17(7):570-7.
- 23. Beverley J, Beebe J. Judgements of moral responsibility in tissue donation cases. Bioethics. 2018 Feb; 32 (2): 83-93.
- 24. Lombard G. Organ donation and the moral responsibility of caregivers. Soins. 2014 Dec; (791): 46-8.
- 25. Food and Drugs, 21 C.F.R. § 1270 (1997).
- 26. Food and Drugs, 21 C.F.R. § 1271 (2001).
- 27. About HRSA. (2018, May 01). Retrieved August 30, 2018, from https://www.hrsa.gov/about/index.htmlpp.
- 28. National Organ Transplantation Act of 1984, Pub L. 98-507, 98 Stat. 2339-2348
- 29. Champney TH. The business of bodies: Ethical perspectives on for-profit body donation companies. Clinical Anatomy. 2015;29(1):25-29. doi:10.1002/ca.22643.
- 30. Grow B, John S. The Body Trade:In the U.S. market for human bodies, anyone can sell the donated dead. Reuters. https://www.reuters.com/investigates/special-report/usa-bodies-brokers/. Published October 24, 2017.
- 31. Riederer BM. Body donations today and tomorrow: What is best practice and why? Clinical Anatomy. 2015;29(1):11-18. doi:10.1002/ca.22641.

Page 3 of 4

- 32. Jones DG. Searching for good practice recommendations on body donation across diverse cultures. Clinical Anatomy. 2015;29(1):55-59. doi:10.1002/ca.22648.
- 33. White E. Man who peddled diseased body parts gets 9 years. Chicago Tribune. http://www.chicagotribune.com/business/ct-biz-body-parts-broker-sentencing-20180522-story.html. Published May 22, 2018.
- 34. Grow B, Schiffman J. The Body Trade: How Reuters bought human body parts and learned a donors tragic story. Reuters. https://www.reuters.com/investigates/special-report/usa-bodies-cody/. Published October 25, 2017.
- 35. Anteby M, Hyman M. Entrepreneurial ventures and whole-body donations: A regional perspective from the United States. Social Science & Medicine. 2008;66(4):963-969. doi:10.1016/j.socscimed.2007.10.023.
- 36. International Federation of Associations of Anatomists. Recommendations of Good Practice for the Donation and Study of Human Bodies and Tissues for Anatomical Examination. 2017.
- 37. Benninger, B., Formally acknowledging donor-cadaver-patients in the basic and clinical science research arena. Clin Anat, 2013. 26(7): p. 810-3.

RELEVANT AMA POLICY

E-6.1.3 Studying Financial Incentives for Cadaveric Organ Donation

Physicians' ethical obligations to contribute to the health of the public and to support access to medical care extend to participating in efforts to increase the supply of organs for transplantation. However, offering financial incentives for donation raises ethical concerns about potential coercion, the voluntariness of decisions to donate, and possible adverse consequences, including reducing the rate of altruistic organ donation and unduly encouraging perception of the human body as a source of profit.

These concerns merit further study to determine whether, overall, the benefits of financial incentives for organ donation outweigh their potential harms. It would be appropriate to carry out pilot studies among limited populations to investigate the effects of such financial incentives for the purpose of examining and possibly revising current policies in the light of scientific evidence. Physicians who develop or participate in pilot studies of financial incentives to increase donation of cadaveric organs should ensure that the study:

- (a) Is strictly limited to circumstances of voluntary cadaveric donation with an explicit prohibition of the selling of organs.
- (b) Is scientifically well designed and clearly defines measurable outcomes and time frames in a written protocol.
- (c) Has been developed in consultation with the population among whom it is to be carried out.
- (d) Has been reviewed and approved by an appropriate oversight body, such as an institutional review board, and is carried out in keeping with guidelines for ethical research.
- (e) Offers incentives of only modest value and at the lowest level that can reasonably be expected to increase organ donation.

AMA Principles of Medical Ethics: I,III,V,VII,VIII,IX

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.

Issued: 2016

Regulation of Tissue Banking H-370.988

Our AMA: (1) supports the Food and Drug Administration's (FDA) proposed regulatory agenda for tissue banking organizations, and urges the FDA to continue working with nationally-recognized tissue banking organizations and other appropriate groups to implement the proposed oversight system; (2) promotes the adoption of the standards for tissue retrieval and processing established by nationally recognized tissue banking organizations that would mandate adherence to specific standards as a condition of licensure and certification for tissues banks; (3) supports FDA registration of all tissue banks; and (4) supports the continued involvement of the medical community in the further effort to ensure the safety and efficacy of the nation's supply of tissues.

Citation: BOT Rep. E, I-89; Reaffirmed: Sunset Report, A-00; Modified and Appended, CSA Rep. 5, I-01; Reaffirmation I-07; Reaffirmed: CSAPH Rep. 01, A-17

Page 4 of 4

State Regulation and Licensing of Human Tissue Banks H-370.989

Our AMA encourages states to require licensing of human tissue banks in a manner consistent with the Food and Drug Administration's federal regulatory requirements.

Citation: (Res. 68, I-87; Reaffirmed: Sunset Report, I-97; Modified: CSA Rep. 5, I-01;

Reaffirmed: CSAPH Rep. 1, A-11

Organ Donation and Honoring Organ Donor Wishes H-370.998

Our AMA: (1) continues to urge the citizenry to sign donor cards and supports continued efforts to educate the public on the desirability of, and the need for, organ donations, as well as the importance of discussing personal wishes regarding organ donation with appropriate family members; and (2) when a good faith effort has been made to contact the family, actively encourage Organ Procurement Organizations and physicians to adhere to provisions of the Uniform Anatomical Gift Act which allows for the procurement of organs when the family is absent and there is a signed organ donor card or advanced directive stating the decedent's desire to donate the organs.

Citation: (CSA Rep. D, I-80; CLRPD Rep. B, I-90; Amended: Res. 504, I-99; Reaffirmed: CSA Rep. 6, A-00; Reaffirmed: CSA Rep. 4, I-02; Reaffirmed: CSAPH Rep. 1, A-12

Organ Donation D-370.985

Our AMA will study potential models for increasing the United States organ donor pool. Citation: Res. 1, A-14; Reaffirmed in lieu of Res. 5, I-14; Reaffirmed in lieu of: Res. 002, I-16

Ethical Procurement of Organs for Transplantation H-370.967

Our AMA will continue to monitor ethical issues related to organ transplantation and develop additional policy as necessary.

Citation: BOT Rep. 13, A-08; Reaffirmed: CEJA Rep. 06, A-18

Resolution: 013

(A-19)

Introduced by: Medical Student Section

Subject: Opposing Office of Refugee Resettlement's Use of Medical and Psychiatric

Records for Evidence in Immigration Court

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, In 2017 it became policy that unaccompanied immigrant minors – children that enter the United States in family units and those that cross individually – must be placed under the custody of Office Refugee Resettlement (ORR) of the Department of Health and Human Services (HHS) 1; and

Whereas, In 2017, 40,810 unaccompanied immigrant children were referred to ORR, where the average length of stay was 41 days²; and

Whereas, Children in ORR custody frequently receive medical and mental health services during their detainment³; and

Whereas, Confidential medical and psychological records and social work case files from ORR are increasingly presented in immigration court as evidence for deportation or further detainment^{4,5}; and

Whereas, Before a child reaches the age of 18 they cannot exercise their own HIPAA rights without the signature of a parent or guardian, and children in detainment are separated from their parents, and therefore do not have access to their own HIPAA rights⁵⁻⁷; and

Whereas, Breaches in patient confidentiality, or the perceived threat thereof, create distrust in the healthcare system and lead to patients delaying or forgoing medical care, particularly in immigrant populations⁸⁻¹⁰; and

Whereas, Undocumented children forcibly separated from parents at the US border have been shown to be at increased risk for post-traumatic stress disorder, anxiety, depression, aggression and suicidal ideation^{11,12}; and

Whereas, Separating children from their parents during development has been linked with later risk of criminality and mental health issues such as bipolar disorder and schizophrenia¹³; and

Whereas, Existing AMA policy calls for our AMA to "work with medical societies and all clinicians to work together with other child-serving sectors to ensure that new immigrant children receive timely and age-appropriate services that support their health and well-being" (D-60.968); and

Whereas, Existing AMA policy directs our AMA to "recommend the U.S. Immigrations and Customs Enforcement refrain from partnerships with private institutions whose facilities do not

Page 2 of 3

1 meet the standards of medical, mental, and dental care as guided by the National Commission 2 on Correctional Health Care" (D-350.983); and

3 4

5

Whereas, Existing AMA policy instructs our AMA to "support protections that prohibit... law enforcement agencies from utilizing information from medical records to pursue immigration enforcement actions against patients who are undocumented" (H-315.966); therefore be it

RESOLVED, That our American Medical Association advocate that healthcare services provided to minors in immigrant detention focus solely on the health and well-being of the children (Directive to Take Action); and be it further

10 11

- 12 RESOLVED. That our AMA condemn the use of confidential medical and psychological records and social work case files as evidence in immigration courts without patient consent. (Directive 13 14 to Take Action)
 - Fiscal Note: Modest between \$1,000 \$5,000.

Received: 05/09/19

References:

- 1. Fact Sheet: Zero Tolerance Immigration Prosecutions Families. Published June 15th, 2018. Accessed September 1st, 2018.
- 2. Facts and Data. Office of Refugee Resettlement. Published June 25th, 2018. Accessed September 1st, 2018.
- 3. Fact Sheet Subject: Unaccompanied Alien Children Program. Unaccompanied Alien Families. Published June 15th 2018. Accessed September 1st, 2018.
- 4. Luthra S and Taylor M. Immigrant Families Placed in Detention Centers Face Health Care Challenges. https://www.washingtonpost.com/national/health-science/immigrant-families-placed-in-detention-centers-face-health-carechallenges/2018/07/02/291410b6-7e2a-11e8-a63f-7b5d2aba7ac5_story.html?utm_term=.7ee308398121. Published July 2nd, 2018. Accessed September 2nd, 2018.
- 5. Nilsen E. Kids who cross the border meet with therapists and social workers. What they say can be used against them. How the Trump administration is using undocumented kids' confidential health information to lock them up. https://www.vox.com/policy-andpolitics/2018/6/18/17449150/family-separation-policy-immigration-dhs-orr-health-records-undocumented-kids. Published June 19th, 2018. Accessed September 1st, 2018.
- 6. How does HIPAA Privacy Rule Apply to Minors. HIPAA help center. https://www.hipaahelpcenter.com/privacy/how-does-hipaaprivacy-rule-apply-to-minors.
- 7. When does the Privacy Rule allow covered entities to disclose protected health information to law enforcement officials? US Department of Health and Human Services Website.https://www.hhs.gov/hipaa/for-professionals/faq/505/what-does-the-privacyrule-allow-covered-entities-to-disclose-to-law-enforcement-officials/index.html. Accessed September 1st, 2018.
- Sanker, P., et al. "Patient Perspectives of Medical Confidentiality." *Journal of General Internal Medicine* 18.8 (2003): 659-669.
 Toomey RB, Umaña-Taylor AJ, Williams DR, Harvey-Mendoza E, Jahromi LB, Updegraff KA. Impact of Arizona's SB 1070 Immigration Law on Utilization of Health Care and Public Assistance Among Mexican-Origin Adolescent Mothers and Their Mother Figures. American Journal of Public Health. 2014;104(Suppl 1):S28-S34. doi:10.2105/AJPH.2013.301655. Hacker K, Chu J, Arsenault L. Marlin RP.
- 10. Martinez O, Wu E, Sandfort T, et al. Evaluating the Impact of Immigration Policies on Health Status Among Undocumented Immigrants: A Systematic Review, Journal of immigrant and minority health / Center for Minority Public Health, 2015;17(3):947-970. doi:10.1007/s10903-013-9968-4. Mok, PLH, et al. "Experience of Child-Parent Separation and Later Risk of Violent Criminality." American Journal of Preventive Medicine (2018).
- 11. American Public Health Association Statement. Separating parents and children at US border is inhumane and sets the stage for a public health crisis. https://www.apha.org/news-and-media/news-releases/apha-news-releases/2018/parent-child-separation. Published June 15, 2018. Accessed September 1st, 2018.
- 12. Teicher, MH. "Childhood trauma and the enduring consequences of forcibly separating children from parents at the United States border." BMC medicine 16.1 (2018): 146.
- 13. Paksarian, D., et al. "A population-based study of the risk of schizophrenia and bipolar disorder associated with parent-child separation during development." Psychological Medicine 45.13 (2015): 2825-2837.

RELEVANT AMA POLICY

Ensuring Access to Health Care, Mental Health Care, Legal and Social Services for Unaccompanied Minors and Other Recently Immigrated Children and Youth D-60.968 Our AMA will work with medical societies and all clinicians to (i) work together with other childserving sectors to ensure that new immigrant children receive timely and age-appropriate services that support their health and well-being, and (ii) secure federal, state, and other funding sources to support those services.

Page 3 of 3

Citation: (Res. 8, I-14

Improving Medical Care in Immigrant Detention Centers D-350.983

Our AMA will: (1) issue a public statement urging U.S. Immigrations and Customs Enforcement Office of Detention Oversight to (a) revise its medical standards governing the conditions of confinement at detention facilities to meet those set by the National Commission on Correctional Health Care, (b) take necessary steps to achieve full compliance with these standards, and (c) track complaints related to substandard healthcare quality; (2) recommend the U.S. Immigrations and Customs Enforcement refrain from partnerships with private institutions whose facilities do not meet the standards of medical, mental, and dental care as guided by the National Commission on Correctional Health Care; and (3) advocate for access to health care for individuals in immigration detention.

Citation: Res. 017, A-17

Patient and Physician Rights Regarding Immigration Status H-315.966

Our AMA supports protections that prohibit U.S. Immigration and Customs Enforcement, U.S. Customs and Border Protection, or other law enforcement agencies from utilizing information from medical records to pursue immigration enforcement actions against patients who are undocumented.

Citation: Res. 018, A-17

Resolution: 014

(A-19)

Introduced by: Medical Student Section

Subject: Disclosure of Funding Sources and Industry Ties of Professional Medical

Associations and Patient Advocacy Organizations

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Professional medical associations serve physicians and patients by improving physician knowledge and skill, engaging in scholarly activity, and working to promote the public health¹; and

Whereas, Patient advocacy groups provide education, outreach, and support services to patients affected by a medical condition²; and

Whereas, These positive contributions can be affected by financial conflicts of interest, especially in cases where for-profit companies' payments comprise a significant proportion of a professional medical association or a patient advocacy group's operating budget^{2,5}; and

Whereas, A 2017 study of patient advocacy groups revealed that disclosure practices around funding sources and amounts, uses of funding, and corporate connections of management were inconsistent⁴; and

Whereas, The study showed 83% of the studied patient advocacy groups received financial support from drug and biotechnology companies and at least 39% had a current or former industry executive on the governing board, indicating a significant conflict of interest⁴; and

Whereas, Patient advocacy groups motivated by their conflicts of interest may advocate for drugs to enter the marketplace prior to sufficient evidence or may advocate for insurance coverage of these drugs despite minimal or no benefits²; and

Whereas, Professional medical associations are also susceptible to conflict of interest as some depend on industry funding for a significant portion of their operating budget, ranging from 25% to 75% in funding from drug and device companies^{5,6}; and

Whereas, Some professional medical associations set guidelines, and the National Academy of Medicine has recommended limiting authors of clinical guidelines to receive less than 50% of their funding from industry financial ties⁷; and

Whereas, Though the National Academy of Medicine recommended a disclosure law to cover industry payments to patient advocacy groups and professional medical associations, such a provision was not included in the Physician Payments Sunshine Act of 2010⁴; and

Whereas, Disclosure engenders the public trust by providing transparency about financial relationships that a physician, physician organization, or professional medical organization has

Page 2 of 6

with industry and enabling the public to weigh that influence on the organization's practices⁵; and

3 4

5

6

Whereas, While the AMA Code of Medical Ethics 11.2.1 and 11.2.4 address transparency of individual physicians in healthcare settings, the Code does not encompass collective transparency beyond the healthcare setting of professional medical associations and patient advocacy organizations; therefore be it

7 8 9

10 11 RESOLVED, That our American Medical Association support guidelines for members of the Federation of Medicine and patient advocacy organizations to disclose donations, sponsorships, and other financial transactions by industry and commercial stakeholders. (New HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/09/19

References:

- 1. Fleming DA. The Moral Agency of professional medical associations: Meeting Obligations to Advocate for Patients and the Public. Annals of Internal Medicine. 2015;163(12):918. doi:10.7326/m15-2527.
- 2. Rose SL. Patient Advocacy Organizations: Institutional Conflicts of Interest, Trust, and Trustworthiness. The Journal of Law, Medicine & Ethics. 2013;41(3):680-687. doi:10.1111/jlme.12078.
- 3. Brody H. Professional Medical Organizations and Commercial Conflicts of Interest: Ethical Issues. The Annals of Family Medicine. 2010;8(4):354-358. doi:10.1370/afm.1140.
- 4. McCoy MS, Carniol M, Chockley K, Urwin JW, Emanuel EJ, Schmidt H. Conflicts of Interest for Patient-Advocacy Organizations. The New England Journal of Medicine. March 2017. doi:10.1056/NEJMsr1610625.
- 5. Schofferman JA, Eskay-Auerbach ML, Sawyer LS, Herring SA, Arnold PM, Muehlbauer EJ. Conflict of interest and professional medical associations: the North American Spine Society experience. The Spine Journal. 2013;13(8):974-979. doi:10.1016/j.spinee.2012.08.019.
- 6. David J. Rothman; Professional Medical Associations and Divestiture from Industry: An Ethical Imperative for Pain Society Leadership, Pain Medicine, Volume 17, Issue 2, 1 February 2016, Pages 218–219, https://doi.org/10.1093/pm/pnv041_2
- 7. Nissen SE. Conflicts of Interest and Professional Medical Associations Progress and Remaining Challenges. *JAMA*. 2017;317(17):1737–1738. doi:10.1001/jama.2017.2516

RELEVANT AMA POLICY

E-11.2.1 Professionalism in Health Care Systems

Containing costs, promoting high-quality care for all patients, and sustaining physician professionalism are important goals. Models for financing and organizing the delivery of health care services often aim to promote patient safety and to improve quality and efficiency. However, they can also pose ethical challenges for physicians that could undermine the trust essential to patient-physician relationships. Payment models and financial incentives can create conflicts of interest among patients, health care organizations, and physicians. They can encourage undertreatment and overtreatment, as well as dictate goals that are not individualized for the particular patient.

Structures that influence where and by whom care is delivered such as accountable care organizations, group practices, health maintenance organizations, and other entities that may emerge in the future can affect patientschoices, the patient-physician relationship, and physicians relationships with fellow health care professionals.

Formularies, clinical practice guidelines, and other tools intended to influence decision making, may impinge on physicians exercise of professional judgment and ability to advocate effectively for their patients, depending on how they are designed and implemented.

Physicians in leadership positions within health care organizations should ensure that practices for financing and organizing the delivery of care:

- (a) Are transparent.
- (b) Reflect input from key stakeholders, including physicians and patients.
- (c) Recognize that over reliance on financial incentives may undermine physician professionalism.
- (d) Ensure ethically acceptable incentives that:
- (i) are designed in keeping with sound principles and solid scientific evidence. Financial incentives should be based on appropriate comparison groups and cost data and adjusted to reflect complexity, case mix, and other factors that affect physician practice profiles. Practice guidelines, formularies, and other tools should be based on best available evidence and developed in keeping with ethics guidance;

Page 3 of 6

- (ii) are implemented fairly and do not disadvantage identifiable populations of patients or physicians or exacerbate health care disparities;
- (iii) are implemented in conjunction with the infrastructure and resources needed to support high-value care and physician professionalism;
- (iv) mitigate possible conflicts between physiciansfinancial interests and patient interests by minimizing the financial impact of patient care decisions and the overall financial risk for individual physicians.
- (e) Encourage, rather than discourage, physicians (and others) to:
- (i) provide care for patients with difficult to manage medical conditions;
- (ii) practice at their full capacity, but not beyond.
- (f) Recognize physiciansprimary obligation to their patients by enabling physicians to respond to the unique needs of individual patients and providing avenues for meaningful appeal and advocacy on behalf of patients.
- (g) Are routinely monitored to:
- (i) identify and address adverse consequences;
- (ii) identify and encourage dissemination of positive outcomes.
- All physicians should:
- (h) Hold physician-leaders accountable to meeting conditions for professionalism in health care systems.
- (i) Advocate for changes in health care payment and delivery models to promote access to high-quality care for all patients.

AMA Principles of Medical Ethics: I,II III,V

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. Issued: 2016

E-11.2.4 Transparency in Health Care

Respect for patients' autonomy is a cornerstone of medical ethics. Patients must rely on their physicians to provide information that patients would reasonably want to know to make informed, well-considered decisions about their health care. Thus, physicians have an obligation to inform patients about all appropriate treatment options, the risks and benefits of alternatives, and other information that may be pertinent, including the existence of payment models, financial incentives; and formularies, guidelines or other tools that influence treatment recommendations and care. Restrictions on disclosure can impede communication between patient and physician and undermine trust, patient choice, and quality of care. Although health plans and other entities may have primary responsibility to inform patient-members about plan provisions that will affect the availability of care, physicians share in this responsibility. Individually, physicians should:

- (a) Disclose any financial and other factors that could affect the patient's care.
- (b) Disclose relevant treatment alternatives, including those that may not be covered under the patient's health plan.
- (c) Encourage patients to be aware of the provisions of their health plan.
- Collectively, physicians should advocate that health plans with which they contract disclose to patient-members:
- (d) Plan provisions that limit care, such as formularies or constraints on referrals.
- (e) Plan provisions for obtaining desired care that would otherwise not be provided, such as provision for off-formulary prescribing.
- (f) Plan relationships with pharmacy benefit management organizations and other commercial entities that have an interest in physicianstreatment recommendations.

AMA Principles of Medical Ethics: I,II,III,V,VI

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.

Issued: 2016

9.6.2 Gifts to Physicians from Industry

Relationships among physicians and professional medical organizations and pharmaceutical, biotechnology, and medical device companies help drive innovation in patient care and contribute to the economic well-being of the community to the ultimate benefit of patients and the public. However, an increasingly urgent challenge for both medicine and industry is to devise ways to preserve strong, productive collaborations at the same time that they take clear effective action to prevent relationships that damage public trust and tarnish the reputation of both parties.

Page 4 of 6

Gifts to physicians from industry create conditions that carry the risk of subtly biasingor being perceived to bias - professional judgment in the care of patients.

To preserve the trust that is fundamental to the patient-physician relationship and public confidence in the profession, physicians should:

- (a) Decline cash gifts in any amount from an entity that has a direct interest in physicianstreatment recommendations.
- (b) Decline any gifts for which reciprocity is expected or implied.
- (c) Accept an in-kind gift for the physician's practice only when the gift:
- (i) will directly benefit patients, including patient education; and
- (ii) is of minimal value.
- (d) Academic institutions and residency and fellowship programs may accept special funding on behalf of trainees to support medical students', residents', and fellows' participation in professional meetings, including educational meetings, provided:
- (i) the program identifies recipients based on independent institutional criteria; and
- (ii) funds are distributed to recipients without specific attribution to sponsors.

AMA Principles of Medical Ethics: II

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.

Issued: 2016

Principles on Corporate Relationships G-630.040

The House of Delegates adopts the following revised principles on Corporate Relationships. The Board will review them annually and, if necessary, make recommendations for revisions to be presented to the House of Delegates.

- (1) GUIDELINES FOR AMA CORPORATE RELATIONSHIPS. Principles to guide AMA's relationships with corporate America were adopted by our AMA House of Delegates at its December 1997 meeting and slightly modified at the June 1998 meeting. Subsequently, they have been edited to reflect the recommendations from the Task Force on Association/Corporate Relations, including among its members experts external to our AMA. Minor edits were also adopted in 2002. The following principles are based on the premise that in certain circumstances, our AMA should participate in corporate arrangements when guidelines are met, which can further our AMA's core strategic focus, retain AMA's independence, avoid conflicts of interest, and guard our professional values.
- (2) OVERVIEW OF PRINCIPLES. The AMA's principles to guide corporate relationships have been organized into the following categories: General Principles that apply to most situations; Special Guidelines that deal with specific issues and concerns; Organizational Review that outlines the roles and responsibilities of the Board of Trustees, AMA Management and other staff units. These guidelines should be reviewed over time to assure their continued relevance to the policies and operations of our AMA and to our business environment. The principles should serve as a starting point for anyone reviewing or developing AMA's relationships with outside groups.
- (3) GENERAL PRINCIPLES. Our AMA's vision and values statement and strategic focus should provide guidance for externally funded relationships. Relations that are not motivated by the association's mission threaten our AMA's ability to provide representation and leadership for the profession. (a) Our AMA's vision and values and strategic focus ultimately must determine whether a proposed relationship is appropriate for our AMA. Our AMA should not have relationships with organizations or industries whose principles, policies or actions obviously conflict with our AMA's vision and values. For example, relationships with producers of products that harm the public health (e.g., tobacco) are not appropriate for our AMA. Our AMA will proactively choose its priorities for external relationships and collaborate in those that fulfill these priorities. (b) The relationship must preserve or promote trust in our AMA and the medical profession. To be effective, medical professionalism requires the public's trust. Corporate relationships that could undermine the public's trust in our AMA or the profession are not acceptable. For example, no relationship should raise questions about the scientific content of our AMA's health information publications, AMA's advocacy on public health issues, or the truthfulness of its public statements. (c) The relationship must maintain our AMA's objectivity with respect to health issues. Our AMA accepts funds or royalties from external organizations only if acceptance does not pose a conflict of interest and in no way impacts the objectivity of the association, its members, activities, programs, or employees. For example, exclusive relationships with manufacturers of health-related products marketed to the public could impair our AMA's objectivity in promoting the health of America. Our AMA's objectivity with respect to health issues should not be biased by external relationships. (d) The activity must provide benefit to the public's

Page 5 of 6

health, patients' care, or physicians' practice. Public education campaigns and programs for AMA or Federation members are potentially of significant benefit. Corporate-supported programs that provide financial benefits to our AMA but no significant benefit to the public or direct professional benefits to AMA or Federation members are not acceptable. In the case of member benefits, external relations must not detract from AMA's professionalism.

(4) SPECIAL GUIDELINES. The following guidelines address a number of special situations where our AMA cannot utilize external funding. There are specific guidelines already in place regarding advertising in publications. (a) Our AMA will provide health and medical information, but should not involve itself in the production, sale, or marketing to consumers of products that claim a health benefit. Marketing healthrelated products (e.g., pharmaceuticals, home health care products) undermines our AMA's objectivity and diminishes its role in representing healthcare values and educating the public about their health and healthcare. (b) Activities should be funded from multiple sources whenever possible. Activities funded from a single external source are at greater risk for inappropriate influence from the supporter or the perception of it, which may be equally damaging. For example, funding for a patient education brochure should be done with multiple sponsors if possible. For the purposes of this guideline, funding from several companies, but each from a different and non-competing industry category (e.g., one pharmaceutical manufacturer and one health insurance provider), does not constitute multiple-source funding. Our AMA recognizes that for some activities the benefits may be so great, the harms so minimal, and the prospects for developing multiple sources of funding so unlikely that single-source funding is a reasonable option. Even so, funding exclusivity must be limited to program only (e.g., asthma conference) and shall not extend to a therapeutic category (e.g., asthma). The Board should review single-sponsored activities prior to implementation to ensure that: (i) reasonable attempts have been made to locate additional sources of funds (for example, issuing an open request for proposals to companies in the category); and (ii) the expected benefits of the project merit the additional risk to our AMA of accepting single-source funding. In all cases of single-source funding, our AMA will guard against conflict of interest. (c) The relationship must preserve AMA's control over any projects and products bearing our AMA name or logo. Our AMA retains editorial control over any information produced as part of a corporate/externally funded arrangement. When an AMA program receives external financial support, our AMA must remain in control of its name, logo, and AMA content, and must approve all marketing materials to ensure that the message is congruent with our AMA's vision and values. A statement regarding AMA editorial control as well as the name(s) of the program's supporter(s) must appear in all public materials describing the program and in all educational materials produced by the program. (This principle is intended to apply only to those situations where an outside entity requests our AMA to put its name on products produced by the outside entity, and not to those situations where our AMA only licenses its own products for use in conjunction with another entity's products.) (d) Relationships must not permit or encourage influence by the corporate partner on our AMA. An AMA corporate relationship must not permit influence by the corporate partner on AMA policies, priorities, and actions. For example, agreements stipulating access by corporate partners to the House of Delegates or access to AMA leadership would be of concern. Additionally, relationships that appear to be acceptable when viewed alone may become unacceptable when viewed in light of other existing or proposed activities. (e) Participation in a sponsorship program does not imply AMA's endorsement of an entity or its policies. Participation in sponsorship of an AMA program does not imply AMA approval of that corporation's general policies, nor does it imply that our AMA will exert any influence to advance the corporation's interests outside the substance of the arrangement itself. Our AMA's name and logo should not be used in a manner that would express or imply an AMA endorsement of the corporation, its policies and/or its products. (f) To remove any appearance of undue influence on the affairs of our AMA, our AMA should not depend on funding from corporate relationships for core governance activities.

Funding core governance activities from corporate sponsors, i.e., the financial support for conduct of the House of Delegates, the Board of Trustees and Council meetings could make our AMA become dependent on external funding for its existence or could allow a supporter, or group of supporters, to have undue influence on the affairs of our AMA. (g) Funds from corporate relationships must not be used to support political advocacy activities. A full and effective separation should exist, as it currently does, between political activities and corporate funding. Our AMA should not advocate for a particular issue because it has received funding from an interested corporation. Public concern would be heightened if it appeared that our AMA's advocacy agenda was influenced by corporate funding.

(5) ORGANIZATIONAL REVIEW. Every proposal for an AMA corporate relationship must be thoroughly screened prior to staff implementation. AMA activities that meet certain criteria requiring further review are forwarded to a committee of the Board of Trustees for a heightened level of scrutiny. (a) As part of its

Page 6 of 6

annual report on the AMA?s performance, activities, and status, the Board of Trustees will present a summary of the AMA?s corporate arrangements to the House of Delegates at each Annual Meeting. (b) Every new AMA Corporate relationship must be approved by the Board of Trustees, or through a procedure adopted by the Board. Specific procedures and policies regarding Board review are as follows: (i) The Board routinely should be informed of all AMA corporate relationships; (ii) Upon request of two dissenting members of the CRT, any dissenting votes within the CRT, and instances when the CRT and the Board committee differ in the disposition of a proposal, are brought to the attention of the full Board; (iii) All externally supported corporate activities directed to the public should receive Board review and approval; (iv) All activities that have support from only one corporation except patient materials linked to CME, within an industry should either be in compliance with ACCME guidelines or receive Board review; and (f) All relationships where our AMA takes on a risk of substantial financial penalties for cancellation should receive Board review prior to enactment. (c) The Executive Vice President is responsible for the review and implementation of each specific arrangement according to the previously described principles. The Executive Vice President is responsible for obtaining the Board of Trustees authorization for externally funded arrangements that have an economic and/or policy impact on our AMA. (d) The Corporate Review Team reviews corporate arrangements to ensure consistency with the principles and quidelines. (i) The Corporate Review Team is the internal, cross-organizational group that is charged with the review of all activities that associate the AMA's name and logo with that of another entity and/or with external funding. (ii) The Review process is structured to specifically address issues pertaining to AMA's policy, ethics, business practices, corporate identity, reputation and due diligence. Written procedures formalize the committee's process for review of corporate arrangements. (iii) All activities placed on the Corporate Review Team agenda have had the senior manager's review and consent, and following CRT approval will continue to require the routine approvals of the Office of Finance and Office of the General Counsel. (iv) The Corporate Review Team reports its findings and recommendations directly to a committee of the Board. (e) Our AMA's Office of Risk Management in consultation with the Office of the General Counsel will review and approve all marketing materials that are prepared by others for use in the U.S. and that bear our AMA's name and/or corporate identity. All marketing materials will be reviewed for appropriate use of AMA's logos and trademarks, perception of implied endorsement of the external entity's policies or products, unsubstantiated claims, misleading, exaggerated or false claims, and reference to appropriate documentation when claims are made. In the instance of international publishing of JAMA and the Archives, our AMA will require review and approval of representative marketing materials by the editor of each international edition in compliance with these principles and guidelines. (6) ORGANIZATIONAL CULTURE AND ITS INFLUENCE ON EXTERNALLY FUNDED PROGRAMS. (a) Organizational culture has a profound impact on whether and how AMA corporate relationships are pursued. AMA activities reflect on all physicians. Moreover, all physicians are represented to some extent by AMA actions. Thus, our AMA must act as the professional representative for all physicians, and not merely as an advocacy group or club for AMA members. (b) As a professional organization, our AMA operates with a higher level of purpose representing the ideals of medicine. Nevertheless, non-profit associations today do require the generation of non-dues revenues. Our AMA should set goals that do not create an undue expectation to raise increasing amounts of money. Such financial pressures can provide an incentive to evade, minimize, or overlook guidelines for fundraising through external sources. (c) Every staff member in the association must be accountable to explicit ethical standards that are derived from the vision, values, and focus areas of the Association. In turn, leaders of our AMA must recognize the critical role the organization plays as the sole nationally representative professional association for medicine in America. AMA leaders must make programmatic choices that reflect a commitment to professional values and the core organizational purpose. BOT Rep. 20, A-99 Consolidated: CLRPD Rep. 3, I-01 Modified: CLRPD Rep. 1, A-03 Modified:

CCB/CLRPD Rep. 3, A-12

Preservation of Political Advocacy by Nonprofit Organizations H-270.968

The AMA continues to oppose a federal initiative that would impose restrictions on advocacy activities of federal grantees that preclude them from both utilizing private funds for advocacy activities as well as delivering government-funded services.

Citation: Res. 216, A-96; Reaffirmed: BOT Rep. 34, A-06; Reaffirmed: BOT Rep. 06, A-16

Resolution: 015

(A-19)

Introduced by: Medical Student Section

Subject: Opposing Mandated Reporting of People Who Question Their Gender

Identity

Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Transgender and gender nonconforming people are defined by the American Psychological Association as those who have a gender identity that is not fully aligned with their sex assigned at birth¹; and

Whereas, An estimated 153,300 of US children age 13-17 years old and 700,000 of US adults identify as transgender or gender nonconforming²; and

Whereas, Compelled disclosure policies, including mandatory reporting laws, represent a growing effort by federal, state, and institutional agencies to increase transparency regarding abuses against vulnerable populations, but must be balanced against the constitutionality of compelled speech by showing there is a compelling reason for the speech to be compelled³⁻⁵; and

Whereas, Proposed Ohio House Bill 658 places explicit burden on educational and healthcare professionals to ascertain parental consent before pursuing subsequent therapeutic intervention for gender nonconforming minor patients⁶; and proposed constitutional amendment in Delaware would change discrimination protections to require disclosure of a student's gender identity/expression to parents before making accommodations in applicable educational programs⁸; and

Whereas, Laws enacted in multiple states have been upheld in court which found that parents have no right to choose a harmful treatment for their child and free speech could be regulated to protect children from harmful or ineffective professional services^{9,10}; and

Whereas, Gender nonconformity is a major risk factor for school victimization among LGBTQ+ (lesbian, gay, bisexual, transgender, queer) youth and may also be a reason for gender nonconforming youth to seek medical or mental health services 11,12; and

Whereas, The two most frequent reasons for LGBTQ+ homelessness--approximately forty percent of homeless youth--are family rejection of sexual orientation or gender identity and being forced out by parents because of sexual orientation or gender identity¹³; and

Whereas, Young LGBTQ+ adults who reported family rejection during adolescence were 8.4 times more likely to report having attempted suicide, 5.9 times more likely to report high levels of depression, 3.4 times more likely to use illegal drugs, and 3.4 times more likely to report having engaged in unprotected sexual intercourse¹⁴; and

Page 2 of 7

Whereas, Sixty-one percent of LGBTQ+ youth report being open about their sexual orientation and/or gender identity at school¹⁵; and

2 3 4

1

Whereas, Twenty-six percent of LGBTQ+ youth do not want to disclose their sexual orientation and/or gender identity to teachers out of fear that those teachers might then tell their parents and that it would impact their education unnecessarily¹⁵; and

6 7 8

9

10 11

5

Whereas, Pursuant to existing AMA policy H-315.983, our AMA believes "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": therefore be it

12 13 14

15

RESOLVED, That our American Medical Association oppose mandated reporting of youth who question or express interest in exploring their gender identity. (New HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/09/19

References:

- 1. American Psychological Association. Guidelines for psychological practice with transgender and gender nonconforming people. *American Psychologist.* 2015; 70(9):832-864. doi: 10.1037/a0039906
- 2. Herman JL, Flores AR, Brown TNT, Wilson BDM, Conron KJ. Age of individuals who identify as transgender in the united states. *The Williams Institute*. 2017; 1-13. https://williamsinstitute.law.ucla.edu/wp-content/uploads/TransAgeReport.pdf.
- 3. Holland KJ, Cortina LM. Compelled Disclosure of College Sexual Assault. American Psychology. 2018; 73(3):256-268.
- 4. Children's Bureau. *Mandated Reporters of Child Abuse and Neglect.* Children's Bureau; 2016:1-3. https://www.childwelfare.gov/topics/systemwide/laws-policies/statutes/manda/.
- 5. Rumsfeld v. Forum for Academic and Institutional Rights (2006).
- 6. Brinkman, Zeltwanger. HB No. 658. 132nd General Assembly. Proposed 2017-2018. http://search-prod.lis.state.oh.us/solarapi/v1/general_assembly_132/bills/hb658/IN/00?format=pdf
- 7. Grasha K. Prosecutor: parents' refusal of transgender treatment made teen suicidal. *Cincinnati.com.* January 26, 2018. https://www.cincinnati.com/story/news/2018/01/26/prosecutor-parent-told-transgender-teen-he-going-hell/1071010001/. 8. 14 Admin. Code 225, Reg. Sess. 941 (Delaware, 2018).
- 9. Green R. Banning therapy to change sexual orientation or gender identity in patients under 18. *Journal of the American Academy of Psychiatry and the Law.* 2017; 45(1):7-11.
- 10. Movement Advancement Project. Conversion Therapy Laws. http://www.lgbtmap.org/equality-maps/conversion_therapy. Updated August 31, 2018.
- 11. Toomey R, Ryan C, Diaz R, Card N, Russell S. Gender-nonconforming lesbian, gay, bisexual, and transgender youth: School victimization and young adult psychosocial adjustment. *Psychology of Sexual Orientation and Gender Diversity*. 2013; 1(S):71-80. 12. Aranmolate R, Bogan DR, Hoard T, Mawson AR. Suicide risk factors among LGBTQ youth: review. *JSM Schizophrenia*. 2017; 2(2):1011.
- 13. Durso LE, Gates GJ. Serving our youth: findings from a national survey of services providers working with lesbian, gay, bisexual and transgender youth who are homeless or at risk of becoming homeless. 2012; 1-15. https://escholarship.org/uc/item/80x75033. 14. Ryan C, Huebner D, Diaz RM, Sanchez J. Family rejection as a predictor of negative health outcomes in white and Latino lesbian, gay, and bisexual young adults. *Pediatrics*. 2009; 123(1):346-352. doi: 10.1542/peds.2007-3524. 15. Human Rights Campaign. Being Out. https://assets2.hrc.org/files/assets/resources/NCOD-Youth-Report.pdf?_ga=2.128173068.1601470003.1535476540-1382593011.1535476540.

RELEVANT AMA POLICY

2.2.2 Confidential Health Care for Minors

Physicians who treat minors have an ethical duty to promote the developing autonomy of minor patients by involving children in making decisions about their health care to a degree commensurate with the child's abilities. A minor's decision-making capacity depends on many factors, including not only chronological age, but also emotional maturity and the individual's medical experience. Physicians also have a responsibility to protect the confidentiality of minor patients, within certain limits.

In some jurisdictions, the law permits minors who are not emancipated to request and receive confidential services relating to contraception, or to pregnancy testing, prenatal care, and

Page 3 of 7

delivery services. Similarly, jurisdictions may permit unemancipated minors to request and receive confidential care to prevent, diagnose, or treat sexually transmitted disease, substance use disorders, or mental illness.

When an unemancipated minor requests confidential care and the law does not grant the minor decision-making authority for that care, physicians should:

- (a) Inform the patient (and parent or guardian, if present) about circumstances in which the physician is obligated to inform the minor's parent/guardian, including situations when:
- (i) involving the patient's parent/guardian is necessary to avert life- or health- threatening harm to the patient;
- (ii) involving the patient's parent/guardian is necessary to avert serious harm to others;
- (iii) the threat to the patient's health is significant and the physician has no reason to believe that parental involvement will be detrimental to the patient's well-being.
- (b) Explore the minor patient's reasons for not involving his or her parents (or guardian) and try to correct misconceptions that may be motivating the patient's reluctance to involve parents.
- (c) Encourage the minor patient to involve his or her parents and offer to facilitate conversation between the patient and the parents.
- (d) Inform the patient that despite the physician's respect for confidentiality the minor patient's parents/guardians may learn about the request for treatment or testing through other means (e.g., insurance statements).
- (e) Protect the confidentiality of information disclosed by the patient during an exam or interview or in counseling unless the patient consents to disclosure or disclosure is required to protect the interests of others, in keeping with ethical and legal guidelines.
- (f) Take steps to facilitate a minor patient's decision about health care services when the patient remains unwilling to involve parents or guardians, so long as the patient has appropriate decision-making capacity in the specific circumstances and the physician believes the decision is in the patient's best interest. Physicians should be aware that states provide mechanisms for unemancipated minors to receive care without parental involvement under conditions that vary from state to state.
- (g) Consult experts when the patient's decision-making capacity is uncertain.
- (h) Inform or refer the patient to alternative confidential services when available if the physician is unwilling to provide services without parental involvement.

AMA Principles of Medical Ethics: 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.

Issued: 2016

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 patients 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.

Page 4 of 7

AMA Principles of Medical Ethics: I,IV

The Opinions in this chapter are offered as ethics guidance for physicians and are not intended Issued: 2016

Support of Human Rights and Freedom H-65.965

Our AMA: (1) continues to support the dignity of the individual, human rights and the sanctity of human life, (2) reaffirms its long-standing policy that there is no basis for the denial to any human being of equal rights, privileges, and responsibilities commensurate with his or her individual capabilities and ethical character because of an individual's sex, sexual orientation, gender, gender identity, or transgender status, race, religion, disability, ethnic origin, national origin, or age; (3) opposes any discrimination based on an individual's sex, sexual orientation, gender identity, race, religion, disability, ethnic origin, national origin or age and any other such reprehensible policies; (4) recognizes that hate crimes pose a significant threat to the public health and social welfare of the citizens of the United States, urges expedient passage of appropriate hate crimes prevention legislation in accordance with our AMA's policy through letters to members of Congress; and registers support for hate crimes prevention legislation, via letter, to the President of the United States.

Citation: CCB/CLRPD Rep. 3, A-14; Reaffirmed in lieu of: Res. 001, I-16; Reaffirmation: A-17

Clarification of Medical Necessity for Treatment of Gender Dysphoria H-185.927

Our AMA: (1) recognizes that medical and surgical treatments for gender dysphoria, as determined by shared decision making between the patient and physician, are medically necessary as outlined by generally-accepted standards of medical and surgical practice; and (2) will advocate for federal, state, and local policies to provide medically necessary care for gender dysphoria.

Citation: Res. 05, A-16

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

Page 5 of 7

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

Page 6 of 7

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; 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

Nondiscriminatory Policy for the Health Care Needs of LGBTQ Populations H-65.976 Our AMA encourages physician practices, medical schools, hospitals, and clinics to broaden any nondiscriminatory statement made to patients, health care workers, or employees to include "sexual orientation, sex, or gender identity" in any nondiscrimination statement.

Citation: Res. 414, A-04; Modified: BOT Rep. 11, A-07; Modified: Res. 08, A-16; Modified: Res. 903. I-17

Confidential Health Services for Adolescents H-60.965Our AMA:

- (1) reaffirms that confidential care for adolescents is critical to improving their health;
- (2) encourages physicians to allow emancipated and mature minors to give informed consent for medical, psychiatric, and surgical care without parental consent and notification, in conformity with state and federal law;
- (3) encourages physicians to involve parents in the medical care of the adolescent patient, when it would be in the best interest of the adolescent. When, in the opinion of the physician, parental involvement would not be beneficial, parental consent or notification should not be a barrier to care:
- (4) urges physicians to discuss their policies about confidentiality with parents and the adolescent patient, as well as conditions under which confidentiality would be abrogated. This

Page 7 of 7

discussion should include possible arrangements for the adolescent to have independent access to health care (including financial arrangements);

- (5) encourages physicians to offer adolescents an opportunity for examination and counseling apart from parents. The same confidentiality will be preserved between the adolescent patient and physician as between the parent (or responsible adult) and the physician;
- (6) encourages state and county medical societies to become aware of the nature and effect of laws and regulations regarding confidential health services for adolescents in their respective jurisdictions. State medical societies should provide this information to physicians to clarify services that may be legally provided on a confidential basis;
- (7) urges undergraduate and graduate medical education programs and continuing education programs to inform physicians about issues surrounding minors' consent and confidential care, including relevant law and implementation into practice;
- (8) encourages health care payers to develop a method of listing of services which preserves confidentiality for adolescents; and
- (9) encourages medical societies to evaluate laws on consent and confidential care for adolescents and to help eliminate laws which restrict the availability of confidential care. Citation: (CSA Rep. A, A-92; Reaffirmed by BOT Rep. 24, A-97; Reaffirmed by BOT Rep. 9, A-98; Reaffirmed: Res. 825, I-04; Reaffirmation A-08; Reaffirmed: CMS Rep. 2, I-14

Resolution: 016

(A-19)

Introduced by: Medical Student Section

Subject: Sexual and Gender Minority Populations in Medical Research

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, In the United States, approximately eight million adults identify as lesbian, gay, or bisexual, and 700,000 adults identify as transgender¹; and

Whereas, In 2016, the National Institute of Minority Health and Health Disparities, part of the National Institutes of Health (NIH), designated sexual and gender minorities (SGM) as a health disparity population for research purposes²; and

Whereas, In 2015, the NIH established a Sexual and Gender Minority Research Office that provides funding earmarked for SGM-specific medical research^{3,4}; and

Whereas, There continues to be a paucity of research regarding health care issues and integrated care interventions affecting lesbian, gay, bisexual, and transgender (LGBT)-identified youth and older adults⁵⁻⁷; and

Whereas, Investigators failing to collect sexual preference data on study participants has been identified as a barrier to detecting health trends among SGM populations⁸; and

 Whereas, Despite the relative scarcity of studies that record SGM identifiers, research has shown significant disparities between SGM groups and between those populations and the general public, such as modifiable risk factors for cardiovascular disease, prevalence and predictors of obesity, mental health and substance use disorders, sexually transmitted infections, and suicidal ideation and suicidality⁹⁻¹⁶; and

Whereas, The U.S. Department of Health and Human Services' Office of Disease Prevention and Health Promotion, as a part of the Healthy People 2020 initiative, set a goal of increasing the number of states that include questions identifying sexual orientation and gender identity on state level surveys and/or data systems¹⁷; and

 Whereas, Collecting data on patients' sexual orientation and gender identity in the electronic health record is supported by multiple sources, including the National Academy of Medicine's 2011 report on LGBT health, Healthy People 2020, the Affordable Care Act, and the Joint Commission¹⁸; and

Whereas, Pursuant to existing AMA policy H-460.909, our AMA believes research priorities and methodology should factor in any systematic variations in disease prevalence or response across groups by race, ethnicity, gender, age, geography, and economic status; and

Whereas, Pursuant to existing AMA policy H-460.907, our AMA encourages research into specific areas affecting the health of SGM populations; and

Page 2 of 5

Whereas, Pursuant to existing AMA policy H-315.967, our AMA supports collection of patient data that is inclusive of sexual orientation/gender identity in medical documentation and related forms for research purposes, but our AMA is unclear in its position on collection of this data in the context of research studies; therefore be it

4 5 6

7

1

3

RESOLVED, That our American Medical Association amend policy H-315.967, "Promoting Inclusive Gender, Sex, and Sexual Orientation Options on Medical Documentation," by addition and deletion as follows:

8 9 10

11

12

13

14

15

16

17

18

19

20

Promoting Inclusive Gender, Sex, and Sexual Orientation Options on Medical Documentation

Our AMA: (1) supports the voluntary inclusion of a patient's biological sex, current gender identity, sexual orientation, and preferred gender pronoun(s) in medical documentation and related forms, including in electronic health records, in a culturally-sensitive and voluntary manner; and (2) will advocate for collection of patient data in medical documentation and in medical research studies, according to current best practices, that is inclusive of sexual orientation/gender identity sexual orientation, gender identity, and other sexual and gender minority traits such as differences/disorders of sex development for the purposes of research into patient and population health. (Modify Current HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/09/19

References:

- Gates GJ. How many people are lesbian, gay, bisexual, or transgender? Williams Institute. 2011. https://williamsinstitute.law.ucla.edu/wp-content/uploads/Gates-How-Many-People-LGBT-Apr-2011.pdf. Accessed June 25, 2018.
- 2. https://www.nimhd.nih.gov/about/directors-corner/message.html. Accessed July 15, 2018.
- 3. https://dpcpsi.nih.gov/sgmro. Accessed July 15, 2018.
- 4. https://grants.nih.gov/grants/guide/pa-files/PA-18-040.html. Accessed July 15, 2018.
- Fisher CB, Mustanski B. Reducing Health Disparities and Enhancing the Responsible Conduct of Research Involving LGBT Youth. Hastings Center Report. 2014;44(s4). doi:10.1002/hast.367.
- Cloyes KG. The Silence of Our Science: Nursing Research on LGBT Older Adult Health. Research in Gerontological Nursing. 2015;9(2):92-104. doi:10.3928/19404921-20151218-02.
- 7. Hughes R, Damin C, Heiden-Rootes K. Where's the LGBT in integrated care research? A systematic review. Families, Systems, & Health. 2017;35(3):308-319. doi:10.1037/fsh0000290
- 8. Meads C, Moore D. Breast cancer in lesbians and bisexual women: systematic review of incidence, prevalence and risk studies. *BMC Public Health*. 2013;13(1). doi:10.1186/1471-2458-13-1127.
- 9. Caceres B, Brody A, Halkitis P, Dorsen C, Yu G, Chyun D. Sexual Orientation Differences in Modifiable Risk Factors for Cardiovascular Disease and Cardiovascular Disease Diagnoses in Men. *LGBT Health*. 2018. doi:10.1089/lgbt.2017.0220.
- 10. Warren JC, Smalley KB, Barefoot KN. Differences in Psychosocial Predictors of Obesity Among LGBT Subgroups. *LGBT Health*. 2016;3(4):283-291. doi:10.1089/lgbt.2015.0076.
- 11. Beach LB, Elasy TA, Gonzales G. Prevalence of Self-Reported Diabetes by Sexual Orientation: Results from the 2014 Behavioral Risk Factor Surveillance System. *LGBT Health*. 2018;5(2):121-130. doi:10.1089/lgbt.2017.0091.
- 12. Cochran SD, Mays VM. Risk of Breast Cancer Mortality Among Women Cohabiting with Same Sex Partners: Findings from the National Health Interview Survey, 1997–2003. *Journal of Womens Health*. 2012;21(5):528-533. doi:10.1089/jwh.2011.3134.
- 13. Dai H. Tobacco Product Use Among Lesbian, Gay, and Bisexual Adolescents. Pediatrics. 2017;139(4):e20163276.
- 14. Mcnamara MC, Ng H. Best practices in LGBT care: A guide for primary care physicians. *Cleveland Clinic Journal of Medicine*. 2016;83(7):531-541. doi:10.3949/ccjm.83a.15148.
- 15. Coleman E et al. Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People, Version 7. *International Journal of Transgenderism,* 13:165-232, 2011. Doi: 10.1080/15532739.2011.700873.
- Sutter M, Perrin P. Discrimination, mental health, and suicidal ideation among LGBTQ people of color. J Couns Psychol. 2016;63(1):98-105. doi:10.1037/cou0000126.
- 17. https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health/objectives. Accessed July 15, 2018.
- 18. Cahill S, Makadon H. Sexual Orientation and Gender Identity Data Collection in Clinical Settings and in Electronic Health Records: A Key to Ending LGBT Health Disparities. *LGBT Health*. 2014;1(1):34-41. doi:10.1089/lgbt.2013.0001

Page 3 of 5

RELEVANT AMA POLICY

Health Care Needs of Lesbian, Gay, Bisexual, Transgender and Queer Populations H-160.991

- 1. Our AMA: (a) believes that the physician's nonjudgmental recognition of patients' sexual orientations, sexual behaviors, and gender identities enhances the ability to render optimal patient care in health as well as in illness. In the case of lesbian, gay, bisexual, transgender, queer/questioning, and other (LGBTQ) patients, this recognition is especially important to address the specific health care needs of people who are or may be LGBTQ; (b) is committed to taking a leadership role in: (i) educating physicians on the current state of research in and knowledge of LGBTQ Health and the need to elicit relevant gender and sexuality information from our patients; these efforts should start in medical school, but must also be a part of continuing medical education; (ii) educating physicians to recognize the physical and psychological needs of LGBTQ patients; (iii) encouraging the development of educational programs in LGBTQ Health; (iv) encouraging physicians to seek out local or national experts in the health care needs of LGBTQ people so that all physicians will achieve a better understanding of the medical needs of these populations; and (v) working with LGBTQ communities to offer physicians the opportunity to better understand the medical needs of LGBTQ patients; and (c) opposes, the use of "reparative" or "conversion" therapy for sexual orientation or gender identity.
- 2. Our AMA will collaborate with our partner organizations to educate physicians regarding: (i) the need for sexual and gender minority individuals to undergo regular cancer and sexually transmitted infection screenings based on anatomy due to their comparable or elevated risk for these conditions; and (ii) the need for comprehensive screening for sexually transmitted diseases in men who have sex with men; (iii) appropriate safe sex techniques to avoid the risk for sexually transmitted diseases; and (iv) that individuals who identify as a sexual and/or gender minority (lesbian, gay, bisexual, transgender, queer/questioning individuals) experience intimate partner violence, and how sexual and gender minorities present with intimate partner violence differs from their cisgender, heterosexual peers and may have unique complicating factors.
- 3. Our AMA will continue to work alongside our partner organizations, including GLMA, to increase physician competency on LGBTQ health issues.
- 4. Our AMA will continue to explore opportunities to collaborate with other organizations, focusing on issues of mutual concern in order to provide the most comprehensive and up-to-date education and information to enable the provision of high quality and culturally competent care to LGBTQ people.

Citation: CSA Rep. C, I-81; Reaffirmed: CLRPD Rep. F, I-91; CSA Rep. 8 - I-94; Appended: Res. 506, A-00; Modified and Reaffirmed: Res. 501, A-07; Modified: CSAPH Rep. 9, A-08; Reaffirmation A-12; Modified: Res. 08, A-16; Modified: Res. 903, I-17; Modified: Res. 904, I-17; Res. 16, A-18; Reaffirmed: CSA

Promoting Inclusive Gender, Sex, and Sexual Orientation Options on Medical Documentation H-315.967

Our AMA: (1) supports the voluntary inclusion of a patient's biological sex, current gender identity, sexual orientation, and preferred gender pronoun(s) in medical documentation and related forms, including in electronic health records, in a culturally-sensitive and voluntary manner; and (2) will advocate for collection of patient data that is inclusive of sexual orientation/gender identity for the purposes of research into patient health.

Citation: Res. 212, I-16; Reaffirmed in lieu of: Res. 008, A-17

PH Rep. 01, I-18

Page 4 of 5

Encouraging Research Into the Impact of Long-Term Administration of Hormone Replacement Therapy in Transgender Patients H-460.907

Our AMA encourages research into the impact of long-term administration of hormone replacement therapy in transgender patients.

Citation: (Res. 512, A-11

Comparative Effectiveness Research H-460.909

The following Principles for Creating a Centralized Comparative Effectiveness Research Entity are the official policy of our AMA:

PRINCIPLES FOR CREATING A CENTRALIZED COMPARATIVE EFFECTIVENESS RESEARCH ENTITY:

- A. Value. Value can be thought of as the best balance between benefits and costs, and better value as improved clinical outcomes, quality, and/or patient satisfaction per dollar spent. Improving value in the US health care system will require both clinical and cost information. Quality comparative clinical effectiveness research (CER) will improve health care value by enhancing physician clinical judgment and fostering the delivery of patient-centered care. B. Independence. A federally sponsored CER entity should be an objective, independent authority that produces valid, scientifically rigorous research.
- C. Stable Funding. The entity should have secure and sufficient funding in order to maintain the necessary infrastructure and resources to produce quality CER. Funding source(s) must safeguard the independence of a federally sponsored CER entity.
- D. Rigorous Scientifically Sound Methodology. CER should be conducted using rigorous scientific methods to ensure that conclusions from such research are evidence-based and valid for the population studied. The primary responsibility for the conduct of CER and selection of CER methodologies must rest with physicians and researchers.
- E. Transparent Process. The processes for setting research priorities, establishing accepted methodologies, selecting researchers or research organizations, and disseminating findings must be transparent and provide physicians and researchers a central and significant role.
- F. Significant Patient and Physician Oversight Role. The oversight body of the CER entity must provide patients, physicians (MD, DO), including clinical practice physicians, and independent scientific researchers with substantial representation and a central decision-making role(s). Both physicians and patients are uniquely motivated to provide/receive quality care while maximizing value.
- G. Conflicts of Interest Disclosed and Minimized. All conflicts of interest must be disclosed and safeguards developed to minimize actual, potential and perceived conflicts of interest to ensure that stakeholders with such conflicts of interest do not undermine the integrity and legitimacy of the research findings and conclusions.
- H. Scope of Research. CER should include long term and short term assessments of diagnostic and treatment modalities for a given disease or condition in a defined population of patients. Diagnostic and treatment modalities should include drugs, biologics, imaging and laboratory tests, medical devices, health services, or combinations. It should not be limited to new treatments. In addition, the findings should be re-evaluated periodically, as needed, based on the development of new alternatives and the emergence of new safety or efficacy data. The priority areas of CER should be on high volume, high cost diagnosis, treatment, and health services for which there is significant variation in practice. Research priorities and methodology should factor in any systematic variations in disease prevalence or response across groups by race, ethnicity, gender, age, geography, and economic status.
- I. Dissemination of Research. The CER entity must work with health care professionals and health care professional organizations to effectively disseminate the results in a timely manner by significantly expanding dissemination capacity and intensifying efforts to communicate to

Page 5 of 5

physicians utilizing a variety of strategies and methods. All research findings must be readily and easily accessible to physicians as well as the public without limits imposed by the federally supported CER entity. The highest priority should be placed on targeting health care professionals and their organizations to ensure rapid dissemination to those who develop diagnostic and treatment plans.

J. Coverage and Payment. The CER entity must not have a role in making or recommending coverage or payment decisions for payers.

K. Patient Variation and Physician Discretion. Physician discretion in the treatment of individual patients remains central to the practice of medicine. CER evidence cannot adequately address the wide array of patients with their unique clinical characteristics, co-morbidities and certain genetic characteristics. In addition, patient autonomy and choice may play a significant role in both CER findings and diagnostic/treatment planning in the clinical setting. As a result, sufficient information should be made available on the limitations and exceptions of CER studies so that physicians who are making individualized treatment plans will be able to differentiate patients to whom the study findings apply from those for whom the study is not representative. Citation: CMS Rep. 5, I-08; Reaffirmed: Res. 203, I-09; Reaffirmation I-10; Reaffirmed: CMS Rep. 05, I-16

Resolution: 017

(A-19)

Introduced by: Medical Student Section

Subject: National Guidelines for Guardianship

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Guardianship is defined as a legal relationship created when a state court grants a person or entity the authority to make decisions on behalf of an incapacitated individual concerning his/her person or property^{1,2}; and

Whereas, Incapacity is defined as the inability "to meet essential requirement for physical health, safety, and self-care even with appropriate technological assistance" (functional incapacity) or the inability to "receive and evaluate information or make or communicate decisions" (cognitive incapacity)^{3,4}; and

Whereas, A guardian is expected to direct an individual's assets and benefits towards "food, clothing, housing, medical care, personal items, and other immediate and reasonably foreseeable needs"²; and

Whereas, Approximately 1.5 million adults in the U.S. are under the care of guardians^{5–7}; and

Whereas, The U.S. Census Bureau estimated within the U.S. there were over 46 million individuals aged 65 and older (2014) and that figure would double by year 2050¹; and

Whereas, Given the combined anticipated growth of the geriatric population and the prevalence of neurodegenerative diseases, more comprehensive guardianship programs and standard state-level guidelines are warranted to ensure continued delivery of quality care^{8,9}; and

Whereas, Guardianship programs are overseen by individual states' laws, regulations, and court systems and there is currently no nationwide system of guardianship in place^{1,2,10–13}; and

Whereas, In September 2016, only 12 states required certification of professional guardians (who may range from family, friends, corporate professionals, or government officials), and in many states, guardians are not required to receive any formal training^{6,14}; and

Whereas, In 2011, the Government Accountability Office (GAO) determined there was widespread failure of guardians to faithfully execute their court-ordered duties including through neglect, abuse, and financial exploitation, inadequate screening and training of, and insufficient oversight of guardians after appointment^{2,15}; and

Whereas, Oversight and evaluation of guardians is often minimal, and courts and public systems are commonly underfunded and understaffed which results in great difficulty enforcing the minimal regulations and protections currently in place^{1,5,7,16}; and

Page 2 of 6

Whereas, Improper granting of guardianship deprives individuals of civil liberties including their right to self-determination, excludes them from the normal decision-making process, and contributes to further isolation and erosion of actual and self-perceived abilities^{2,17,18}; and

4 5

6

7

Whereas, Poor collection and management of guardianship data across state governments and court systems, in addition to the lack of guardian registries in many states have created barriers to developing evidence-based regulatory and legislative solutions to abuses by guardians^{10,13}; and

8 9 10

Whereas, The lack of standardization for evaluating indications for guardianship in the healthcare setting contributes to delays in process initiation, decreased prompt access to follow-up services, and increased number of medically unnecessary admission days and total expenses¹³; and

13 14 15

11

12

Whereas, Current AMA policy does not address the disparities in guardianship laws that have enabled numerous cases of abuse and left vulnerable those they are meant to protect; therefore be it

17 18

16

RESOLVED, That our American Medical Association collaborate with relevant stakeholders to advocate for federal creation and adoption of national standards for guardianship programs, appropriate program funding measures, and quality control measures. (Directive to Take Action)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 05/09/19

References

- 1. Senate US, Larin KA. GAO-17-33: Elder Abuse The Extent of Abuse by Guardians Is Unknown, but Some Measures Are Being Taken to Help Protect Older Adults.; 2016.
- 2. Brown K. GAO-11-678: Incapacitated Adults Oversight of Federal Fiduciaries and Court- Appointed Guardians Needs Improvement.: 2011.
- 3. American Bar Association. Capacity Definition & Initiation of Guardianship Proceedings.; 2016.
- 4. Marson DC. Clinical and ethical aspects of financial capacity in dementia: a commentary. Am J Geriatr Psychiatry. 2013;21(4):392-0. doi:10.1097/JGP.0b013e31826682f4.
- 5. National Council on Disability. Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination.; 2018.
- 6. Office of Senator Susan Collins. Senate Aging Committee Examines Financial Exploitation by Guardians.
- https://www.collins.senate.gov/newsroom/senate-aging-committee-examines-financial-exploitation-guardians. Published 2018.
- 7. Gurnon E. Guardianship in the U.S.: Protection or Exploitation? Forbes.
- 8. Brown K. GAO-13-498: Elder Justice More Federal Coordination and Public Awareness Needed.; 2013.
- Bandy RJ, Helft PR, Bandy RW, Torke AM. Medical decision-making during the guardianship process for incapacitated, hospitalized adults: A descriptive cohort study. J Gen Intern Med. 2010;25(10):1003-1008. doi:10.1007/s11606-010-1351-8.
 Dong X. Elder Abuse - Research, Practice, and Policy. (Dong X, ed.). Springer International Publishing; 2017. doi:10.1007/978-
- 11. Gibson L. Giving Courts the Information Necessary to Implement Limited Guardianships: Are We There Yet? J Gerontol Soc Work. 2011;54(8):803-818. doi:10.1080/01634372.2011.604668.
- 12. Patyi JY, li AM. Guardianship And Medicaid: The Ins And Outs. 2018; (February 2014):1-3.
- 13. Dong XQ. Elder abuse: Systematic review and implications for practice. J Am Geriatr Soc. 2015;63(6):1214-1238. doi:10.1111/jgs.13454.
- 14. Matt Jameson J, Riesen T, Polychronis S, et al. Guardianship and the potential of supported decision making with individuals with disabilities. Res Pract Pers with Sev Disabil. 2015;40(1):36-51. doi:10.1177/1540796915586189.
- 15. Kutz G. GAO-10-1046: Guardianships Cases of Financial Exploitation, Neglect, and Abuse of Seniors.; 2010.
- 16. Indiana Adult Guardianship State Task Force. Who's Overseeing the Overseers? A Report on the State of Adult Guardianship in Indiana.; 2012.
- 17. Page KS, Hinrichs KLM. Swimming against the Tide: A Case Study on the Removal of Conservatorship and Guardianship. Clin Gerontol. 2017;40(1):35-42. doi:10.1080/07317115.2016.1177767.
- 18. Salzman L. Rethinking Guardianship (Again): Substituted Decision Making As A Violation Of The Integration Mandate Of Title II Of The Americans With Disabilities Act. Univ Color Law Rev. 2010;81:157-245.

Page 3 of 6

RELEVANT AMA POLICY

Elder Mistreatment D-515.985

Our AMA:

- 1. Encourages all physicians caring for the elderly to become more proactive in recognizing and treating vulnerable elders who may be victims of mistreatment through prevention and early identification of risk factors in all care settings. Encourage physicians to participate in medical case management and APS teams and assume greater roles as medical advisors to APS services.
- 2. Promotes collaboration with the Liaison Committee on Medical Education and the Association of American Medical Colleges, as well as the Commission on Osteopathic College Accreditation and American Association of Colleges of Osteopathic Medicine, in establishing training in elder mistreatment for all medical students; such training could be accomplished by local arrangements with the state APS teams to provide student rotations on their teams. Physician responsibility in cases of elder mistreatment could be part of the educational curriculum on professionalism and incorporated into questions on the US Medical Licensing Examination and Comprehensive Osteopathic Medical Licensing Examination.
- 3. Encourages the development of curricula at the residency level and collaboration with residency review committees, the Accreditation Council for Graduate Medical Education, specialty boards, and Maintenance of Certification programs on the recognition of elder mistreatment and appropriate referrals and treatment.
- 4. Encourages substantially more research in the area of elder mistreatment.
- 5. Encourages the US Department of Health and Human Services, Office of Human Research Protections, which provides oversight for institutional review boards, and the Association for the Accreditation of Human Research Protection Programs to collaborate on establishing guidelines and protocols to address the issue of vulnerable subjects and research subject surrogates, so that research in the area of elder mistreatment can proceed.
- 6. Encourages a national effort to reach consensus on elder mistreatment definitions and rigorous objective measurements so that interventions and outcomes of treatment can be evaluated.
- 7. Encourages adoption of legislation, such as the Elder Justice Act, that promotes clinical, research, and educational programs in the prevention, detection, treatment, and intervention of elder abuse, neglect, and exploitation.

Citation: (CSAPH Rep. 7, A-08; Reaffirmed: CMS Rep. 8, I-13

Elder Mistreatment H-515.961

Our AMA recognizes: (1) elder mistreatment as a serious and pervasive public health problem that requires an organized effort from physicians and all medical professionals to improve the timely recognition and provision of clinical care in vulnerable elders who experience mistreatment; and (2) the importance of an interdisciplinary and collaborative approach to this issue, and encourage states to bring together teams with representatives from medicine, nursing, social work, adult protective services (APS), criminal and civil law, and law enforcement to develop appropriate interventions and evaluate their effectiveness.

Citation: CSAPH Rep. 7, A-08; Reaffirmed: CSAPH Rep. 01, A-18

Health Care Costs of Violence and Abuse Across the Lifespan D-515.984

- 1. Our AMA urges the National Academies of Sciences, Engineering, and Medicine to continue to study the impact and health care costs of violence and abuse across the lifespan.
- 2. Our AMA encourages the National Institutes of Health, the Agency for Healthcare Research and Quality, and the Centers for Disease Control and Prevention to conduct research on the cost savings resulting from health interventions on violence and abuse.
- 3. Our AMA encourages the appropriate federal agencies to increase funding for research on the impact and health care costs of elder mistreatment.

Citation: Res. 431, A-08; Modified: CSAPH Rep. 01, A-18

Family and Intimate Partner Violence H-515.965

(1) Our AMA believes that all forms of family and intimate partner violence are major public health issues and urges the profession, both individually and collectively, to work with other interested parties to prevent such violence and to address the needs of victims. Physicians have a major role in lessening the prevalence, scope and severity of child maltreatment, intimate partner violence, and elder abuse, all of which fall under the rubric of family violence. To support physicians in practice, our AMA will continue to

Page 4 of 6

campaign against family violence and remains open to working with all interested parties to address violence in US society. Our AMA's efforts will be guided, in part, by its Advisory Council on Family Violence.

- (2) Our AMA believes that all physicians should be trained in issues of family and intimate partner violence through undergraduate and graduate medical education as well as continuing professional development. The AMA, working with state, county and specialty medical societies as well as academic medical centers and other appropriate groups such as the Association of American Medical Colleges, should develop and disseminate model curricula on violence for incorporation into undergraduate and graduate medical education, and all parties should work for the rapid distribution and adoption of such curricula when developed. These curricula should include coverage of the diagnosis, treatment, and reporting of child maltreatment, intimate partner violence, and elder abuse and provide training on interviewing techniques, risk assessment, safety planning, and procedures for linking with resources to assist victims. Our AMA supports the inclusion of questions on family violence issues on licensure and certification tests.
- (3) The prevalence of family violence is sufficiently high and its ongoing character is such that physicians, particularly physicians providing primary care, will encounter victims on a regular basis. Persons in clinical settings are more likely to have experienced intimate partner and family violence than non-clinical populations. Thus, to improve clinical services as well as the public health, our AMA encourages physicians to:
- (a) Routinely inquire about the family violence histories of their patients as this knowledge is essential for effective diagnosis and care;
- (b) Upon identifying patients currently experiencing abuse or threats from intimates, assess and discuss safety issues with the patient before he or she leaves the office, working with the patient to develop a safety or exit plan for use in an emergency situation and making appropriate referrals to address intervention and safety needs as a matter of course;
- (c) After diagnosing a violence-related problem, refer patients to appropriate medical or health care professionals and/or community-based trauma-specific resources as soon as possible;
- (d) Have written lists of resources available for victims of violence, providing information on such matters as emergency shelter, medical assistance, mental health services, protective services and legal aid;
- (e) Screen patients for psychiatric sequelae of violence and make appropriate referrals for these conditions upon identifying a history of family or other interpersonal violence;
- (f) Become aware of local resources and referral sources that have expertise in dealing with trauma from victimization;
- (g) Be alert to men presenting with injuries suffered as a result of intimate violence because these men may require intervention as either victims or abusers themselves:
- (h) Give due validation to the experience of victimization and of observed symptomatology as possible sequelae;
- (i) Record a patient's victimization history, observed traumata potentially linked to the victimization, and referrals made:
- (j) Become involved in appropriate local programs designed to prevent violence and its effects at the community level;
- (4) Within the larger community, our AMA: (a) Urges hospitals, community mental health agencies, and other helping professions to develop appropriate interventions for all victims of intimate violence. Such interventions might include individual and group counseling efforts, support groups, and shelters.
- (b) Believes it is critically important that programs be available for victims and perpetrators of intimate violence.
- (c) Believes that state and county medical societies should convene or join state and local health departments, criminal justice and social service agencies, and local school boards to collaborate in the development and support of violence control and prevention activities.
- (5) With respect to issues of reporting, our AMA strongly supports mandatory reporting of suspected or actual child maltreatment and urges state societies to support legislation mandating physician reporting of elderly abuse in states where such legislation does not currently exist. At the same time, our AMA opposes the adoption of mandatory reporting laws for physicians treating competent, non-elderly adult victims of intimate partner violence if the required reports identify victims. Such laws violate basic tenets of medical ethics. If and where mandatory reporting statutes dealing with competent adults are adopted, the AMA believes the laws must incorporate provisions that: (a) do not require the inclusion of victims' identities:
- (b) allow competent adult victims to opt out of the reporting system if identifiers are required;

Page 5 of 6

- (c) provide that reports be made to public health agencies for surveillance purposes only;
- (d) contain a sunset mechanism; and
- (e) evaluate the efficacy of those laws. State societies are encouraged to ensure that all mandatory reporting laws contain adequate protections for the reporting physician and to educate physicians on the particulars of the laws in their states.
- (6) Substance abuse and family violence are clearly connected. For this reason, our AMA believes that:
- (a) Given the association between alcohol and family violence, physicians should be alert for the presence of one behavior given a diagnosis of the other. Thus, a physician with patients with alcohol problems should screen for family violence, while physicians with patients presenting with problems of physical or sexual abuse should screen for alcohol use.
- (b) Physicians should avoid the assumption that if they treat the problem of alcohol or substance use and abuse they also will be treating and possibly preventing family violence.
- (c) Physicians should be alert to the association, especially among female patients, between current alcohol or drug problems and a history of physical, emotional, or sexual abuse. The association is strong enough to warrant complete screening for past or present physical, emotional, or sexual abuse among patients who present with alcohol or drug problems.
- (d) Physicians should be informed about the possible pharmacological link between amphetamine use and human violent behavior. The suggestive evidence about barbiturates and amphetamines and violence should be followed up with more research on the possible causal connection between these drugs and violent behavior.
- (e) The notion that alcohol and controlled drugs cause violent behavior is pervasive among physicians and other health care providers. Training programs for physicians should be developed that are based on empirical data and sound theoretical formulations about the relationships among alcohol, drug use, and violence.

Citation: (CSA Rep. 7, I-00; Reaffirmed: CSAPH Rep. 2, I-09

E-8.10 Preventing, Identifying and Treating Violence and Abuse

All patients may be at risk for interpersonal violence and abuse, which may adversely affect their health or ability to adhere to medical recommendations. In light of their obligation to promote the well-being of patients, physicians have an ethical obligation to take appropriate action to avert the harms caused by violence and abuse.

To protect patientswell-being, physicians individually should:

- (a) Become familiar with:
- (i) how to detect violence or abuse, including cultural variations in response to abuse;
- (ii) community and health resources available to abused or vulnerable persons;
- (iii) public health measures that are effective in preventing violence and abuse;
- (iv) legal requirements for reporting violence or abuse.
- (b) Consider abuse as a possible factor in the presentation of medical complaints.
- (c) Routinely inquire about physical, sexual, and psychological abuse as part of the medical history.
- (d) Not allow diagnosis or treatment to be influenced by misconceptions about abuse, including beliefs that abuse is rare, does not occur in normalfamilies, is a private matter best resolved without outside interference, or is caused by victimsown actions.
- (e) Treat the immediate symptoms and sequelae of violence and abuse and provide ongoing care for patients to address long-term consequences that may arise from being exposed to violence and abuse.
- (f) Discuss any suspicion of abuse sensitively with the patient, whether or not reporting is legally mandated, and direct the patient to appropriate community resources.
- (g) Report suspected violence and abuse in keeping with applicable requirements. Before doing so, physicians should:
- (i) inform patients about requirements to report;
- (ii) obtain the patients informed consent when reporting is not required by law. Exceptions can be made if a physician reasonably believes that a patients refusal to authorize reporting is coerced and therefore does not constitute a valid informed treatment decision.
- (h) Protect patient privacy when reporting by disclosing only the minimum necessary information. Collectively, physicians should:
- (i) Advocate for comprehensive training in matters pertaining to violence and abuse across the continuum of professional education.

Page 6 of 6

(j) Provide leadership in raising awareness about the need to assess and identify signs of abuse, including advocating for guidelines and policies to reduce the volume of unidentified cases and help ensure that all patients are appropriately assessed.

- (k) Advocate for mechanisms to direct physicians to community or private resources that might be available to aid their patients.
- (I) Support research in the prevention of violence and abuse and collaborate with public health and community organizations to reduce violence and abuse.
- (m) Advocate for change in mandatory reporting laws if evidence indicates that such reporting is not in the best interests of patients.

AMA Principles of Medical Ethics: I,III

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.

Issued: 2016

Resolution: 018

(A-19)

Introduced by: Medical Student Section

Subject: Support for Requiring Investigations into Deaths of Children in Foster Care

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Around 670,000 children in the U.S will spend time in foster care in any given year, and the number of children in foster care has been increasing since 2012¹⁻⁴; and

2 3 4

5

6

1

Whereas, Children in foster care are one of the most vulnerable populations, often suffering from a higher likelihood of early adverse childhood experiences and disproportionately affected by lack of appropriate housing, behavioral problems, and the disparities associated with minority populations^{2,8-10};

7 8 9

10 11 Whereas, A series of highly-publicized episodes of abuse, neglect, and child deaths in the forprofit foster care system prompted the Senate Finance Committee to conduct an investigation into the privatization of foster care services, and the Committee published a report of their findings in 2017^{3,5,6}; and

12 13 14

Whereas, The Senate Finance Committee report found that children in the foster care system die at an alarmingly high rate that is 42% higher than the national death rate for children with similar health conditions and risk factors, and 70% of these deaths were unexpected^{3,7}; and

16 17 18

15

Whereas, These deaths were often found to have occurred in cases in which children had been placed with foster parents who had a record of abuse;^{3,5} and

19 20 21

Whereas, In some cases children were placed in homes with individuals convicted of kidnapping and other serious crimes, with individuals who had substance abuse problems, and in the care of caretakers who had previously failed foster care placements;^{3,5,6,7} and

23 24 25

22

Whereas, Investigations were conducted in only 15% of deaths with no subsequent action or autopsy performed in all other deaths^{3,7}; and

26 27 28

Whereas, The report found that policies and procedures meant to monitor child welfare and providers' performance and outcomes were not consistently followed³; and

29 30 31

Whereas, AMA policy H-515.960 exhorts "physicians [to] act as advocates for children, and as such, have a responsibility legally and otherwise, to protect children when there is a suspicion of abuse"; therefore be it

33 34 35

36 37

32

RESOLVED, That our American Medical Association support legislation requiring investigations into the deaths of children in the foster care system that occur while the child is in the foster care system. (New HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/09/19

Page 2 of 3

References:

- 1. Child Welfare Information Gateway. (2017). Foster care statistics 2015. Washington, DC: U.S. Department of Health and Human Services, Children's Bureau.
- 2. The AFCARS Report [reports]. Washington, D.C.: U.S. Department of Health & Human Services, Administration for Children and Families; October 20, 2017. https://www.acf.hhs.gov/sites/default/files/cb/afcarsreport24.pdf Accessed March 24, 2018.
- 3. Executive Summary [Committee report]. Washington, D.C.: U.S. Senate Committee of Finance; October 16, 2017. https://www.finance.senate.gov/imo/media/doc/Executive%20Summary.pdf Accessed March 24, 2018.
- 4. Number Of Children in Foster Care Continues To Increase [press release]. Washington, D.C.: U.S. Department of Health & Human Services, Administration for Children and Families; November 30, 2017. https://www.acf.hhs.gov/media/press/2017/number-of-children-in-foster-care-continues-to-increase Accessed March 24, 2018.
- 5. Roston, A and Singer-Vine, J. Fostering Profits: Abuse And Neglect At America's Biggest For-profit Foster Care Company. BuzzFeed News. February 20, 2015. https://www.buzzfeed.com/aramroston/fostering-profits?utm_term=.tsKD4aDK#.ermVDPVW Accessed October 20, 2017.
- 6. Jauregui, A. Sherill Small, Foster Mother, Charged In Murder Of 2-Year-Old Texas Girl. HuffPost News. August 6, 2013. https://www.huffingtonpost.com/2013/08/06/sherill-small-foster-mother-murder-girl_n_3712761.html Accessed October 20, 2017.
- 7. Grim, R and Chavez, A. Children Are Dying At Alarming Rates in Foster Care, and Nobody Is Bothering To Investigate. The Intercept. October 18, 2017. https://theintercept.com/2017/10/18/foster-care-children-deaths-mentor-network/ Accessed October 20, 2017.
- 8. Hobbs, GF et al. Abuse of children in foster and residential care, Child Abuse & Neglect, 1999;23(12):1239-1252.
- 9. Bramlett, MD and Radel, LF. Adverse Family Experiences Among Children in Nonparental Care, 2011-2012. National Health Statistics Reports. 2014;74:1-8
- 10. Barth, RP and Blackwell, DL. Death Rates Among California's Foster Care and Former Foster Care Populations. Children and Youth Services Review. 1998;20(7):577-604.

RELEVANT AMA POLICY

Addressing Healthcare Needs of Children in Foster Care H-60.910

Our AMA advocates for comprehensive and evidence-based care that addresses the specific health care needs of children in foster care.

Citation: Res. 907, I-17

Identifying and Reporting Suspected Child Abuse H-515.960

- 1. Our American Medical Association recognizes that suspected child abuse is being underreported by physicians.
- 2. Our AMA supports development of a comprehensive educational strategy across the continuum of professional development that is designed to improve the detection, reporting, and treatment of child maltreatment. Training should include specific knowledge about child protective services policies, services, impact on families, and outcomes of intervention.
- 3. Our AMA supports the concept that physicians act as advocates for children, and as such, have a responsibility legally and otherwise, to protect children when there is a suspicion of abuse.
- 4. Our AMA recognizes the need for ongoing studies to better understand physicians failure to recognize and report suspected child abuse.
- 5. Our AMA acknowledges that conflicts often exist between physicians and child protective services, and that physicians and child protective services should work more collaboratively, including the joint development of didactic programs designed to foster increased interaction and to minimize conflicts or distrust.
- 6. Our AMA supports efforts to develop multidisciplinary centers of excellence and adequately trained clinical response teams to foster the appropriate evaluation, reporting, management, and support of child abuse victims.
- 7. Our AMA encourages all state departments of protective services to have a medical director or other liaison who communicates with physicians and other health care providers.
- 8. Our AMA will support state and federal-run child protective services in reporting child abuse and neglect in the military to the Family Advocacy Program within the Department of Defense. Citation: CSAPH Rep. 2, I-09; Appended: Res. 411, A-18

Family Violence-Adolescents as Victims and Perpetrators H-515.981

The AMA (1) (a) encourages physicians to screen adolescents about a current or prior history of maltreatment. Special attention should be paid to screening adolescents with a history of alcohol and drug misuse, irresponsible sexual behavior, eating disorders, running away, suicidal behaviors, conduct disorders, or psychiatric disorders for prior occurrences of maltreatment; and (b) urges physicians to consider issues unique to adolescents when screening youths for abuse or neglect. (2) encourages state medical society violence prevention committees to work with child protective service agencies to develop specialized services for maltreated adolescents, including better access to health services, improved foster care, expanded shelter and independent living facilities, and treatment programs. (3) will investigate research and resources on effective parenting of adolescents to identify ways in which physicians can promote parenting styles that reduce stress

Page 3 of 3

and promote optimal development. (4) will alert the national school organizations to the increasing incidence of adolescent maltreatment and the need for training of school staff to identify and refer victims of maltreatment. (5) urges youth correctional facilities to screen incarcerated youth for a current or prior history of abuse or neglect and to refer maltreated youth to appropriate medical or mental health treatment programs. (6) encourages the National Institutes of Health and other organizations to expand continued research on adolescent initiation of violence and abuse to promote understanding of how to prevent future maltreatment and family violence.

Citation: (CSA Rep. I, A-92; Reaffirmed: CSA Rep. 8, A-03; Modified: CSAPH Rep. 1, A-13

Importance of Autopsies H-85.954

- 1. Our AMA supports seeking the cooperation of the National Advisory Council on Aging of the National Institutes of Health in recommending to physicians, hospitals, institutes of scientific learning, universities, and most importantly the American people the necessity of autopsy for pathological correlation of the results of the immeasurable scientific advancements which have occurred in recent years. Our AMA believes that the information garnered from such stringent scientific advancements and correlation, as well as coalitions, should be used in the most advantageous fashion; and that the conclusions obtained from such investigations should be widely shared with the medical and research community and should be interpreted by these groups with the utmost scrutiny and objectivity.
- 2. Our AMA: (a) supports the efforts of the Institute of Medicine and other national organizations in formulating national policies to modernize and promote the use of autopsy to meet present and future needs of society; (b) promotes the use of updated autopsy protocols for medical research, particularly in the areas of cancer, cardiovascular, occupational, and infectious diseases; (c) promotes the revision of standards of accreditation for medical undergraduate and graduate education programs to more fully integrate autopsy into the curriculum and require postmortems as part of medical educational programs; (d) encourages the use of a national computerized autopsy data bank to validate technological methods of diagnosis for medical research and to validate death certificates for public health and the benefit of the nation; (e) requests The Joint Commission to consider amending the Accreditation Manual for Hospitals to require that the complete autopsy report be made part of the medical record within 30 days after the postmortem; (f) supports the formalization of methods of reimbursement for autopsy in order to identify postmortem examinations as medical prerogatives and necessary medical procedures: (a) promotes programs of education for physicians to inform them of the value of autopsy for medical legal purposes and claims processing, to learn the likelihood of effects of disease on other family members, to establish the cause of death when death is unexplained or poorly understood, to establish the protective action of necropsy in litigation, and to inform the bereaved families of the benefits of autopsy; and (h) promotes the incorporation of updated postmortem examinations into risk management and quality assurance programs in hospitals.
- 3. Our AMA reaffirms the fundamental importance of the autopsy in any effective hospital quality assurance program, and urges physicians and hospitals to increase the utilization of the autopsy so as to further advance the cause of medical education, research and quality assurance.
- 4. Our AMA representatives to the Liaison Committee on Medical Education ask that autopsy rates and student participation in autopsies continue to be monitored periodically and that the reasons that schools do or do not require attendance be collected. Our AMA will continue to work with other interested groups to increase the rate of autopsy attendance.
- 5. Our AMA requests that the National Committee on Quality Assurance (NCQA) and other accrediting bodies encourage the performance of autopsies to yield benchmark information for all managed care entities seeking accreditation.
- 6. Our AMA calls upon all third party payers, including CMS, to provide adequate payment directly for autopsies, and encourages adequate reimbursement by all third party payers for autopsies.
- 7. It is the policy of our AMA: (a) that the performance of autopsies constitutes the practice of medicine; and (b) in conjunction with the pathology associations represented in the AMA House, to continue to implement all the recommendations regarding the effects of decreased utilization of autopsy on medical education and research, quality assurance programs, insurance claims processing, and cost containment.
- 8. Our AMA affirms the importance of autopsies and opposes the use of any financial incentives for physicians who acquire autopsy clearance.

Citation: (CCB/CLRPD Rep. 3, A-14

Resolution: 019

(A-19)

Introduced by: Medical Student Section

Subject: Opposition to Requirements for Gender-Based Medical Treatments for

Athletes

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Differences of Sex Development (DSD), also known as intersex, are defined as congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical¹; and

Whereas, The estimated incidence of DSD ranges from 1 in 5,000 ambiguous genitalia to 1 in 1,500 for atypical genitalia^{2,3,4}; and

Whereas, A 2014 study supported by the International Association of Athletics Federations (IAAF) and the World Anti-Doping Agency found that 5 of 839 elite female athletes were diagnosed with hyperandrogenic 46 XY differences of sex development after medical examination⁵; and

Whereas, In 2011, the Women's Sports Foundation (WSF) released a position statement arguing that testing female athletes' testosterone levels would be "problematic and ill-advised," noting that widely-varying natural levels of testosterone in male athletes are not subject to the same scrutiny⁶; and

 Whereas, The same WSF position statement also argued that it would be inappropriate to single out female athletes with naturally higher testosterone levels for exclusion from competition while other competitive advantages such as height, access to coaching from a young age, or upbringing in a high altitude are not restricted⁶; and

Whereas, In April 2018, the IAAF imposed new regulations that require female athletes to maintain their blood testosterone levels below five nmol/L to compete in Restricted Events in International Competitions^{7,8}; and

Whereas, The IAAF regulations were based on a study commissioned by the IAAF published in the *British Journal of Sports Medicine* to investigate evidence of elevated testosterone levels and improved athletic performance⁹; and

Whereas, Independent researchers analyzed the data used for the IAAF study and found that the performance data used in the study's analysis was either anomalous or inaccurate 17% to 33% of the time, calling into question the study itself, with some experts calling for retraction^{10,11}; and

Whereas, These new regulations have led the IAAF to request that female athletes with naturally high testosterone levels undergo medically unnecessary interventions to lower their testosterone levels to be allowed to participate in competitions, a request that is opposed by

Page 2 of 3

Canadian Centre for Ethics in Sport, the Canadian Association for the Advancement of Women in Sport and Physical Activity^{12,13,14,15,16}; and

3 4 5

1

2

Whereas, More than 200 genetic polymorphisms have been associated with improved athletic performance, yet none of these variations lead to the disqualification of athletes^{17,18}; and

many including the Human Rights Watch, the Sport and Recreation Minister of South Africa, the

Whereas, There is no upper limit for testosterone levels imposed on male athletes, and those with male hypogonadism can apply for an exemption to take steroids to increase testosterone levels, compared to female athletes with hyperandrogenism who can be disqualified unless they pursue medical treatments or surgery to lower these levels¹⁹; and

11 12 13

10

Whereas, The AMA has previously taken stances opposing medically unnecessary services (H-470.978, H-525.987); therefore be it

14 15

> RESOLVED, That our American Medical Association oppose any regulations requiring mandatory medical treatment or surgery for athletes with Differences of Sex Development (DSD) to be allowed to compete in alignment with their identity (Directive to Take Action); and be it further

20 21

22

RESOLVED, That our AMA oppose the creation of distinct hormonal guidelines to determine gender classification for athletic competitions. (Directive to Take Action)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 05/09/19

References:

- 1. Consortium on the Management of Disorders of Sex Development. Clinical Guidelines for the Management of Disorders of Sex Development in Childhood.; 2006. http://www.dsdguidelines.org/files/clinical.pdf. Accessed December 28, 2017.
- 2. Leidolf EM, Curran M, Scout, Bradford J. Intersex Mental Health and Social Support Options in Pediatric Endocrinology Training Programs. J Homosex. 2008;54(3):233-242. doi:10.1080/00918360801982074.
- 3. Thyen U, Lanz K, Holterhus P-M, Hiort O. Epidemiology and Initial Management of Ambiguous Genitalia at Birth in Germany. Horm Res Paediatr. 2006;66(4):195-203. doi:10.1159/000094782.
- 4. Blackless M, Charuvastra Á, Derryck A, Fausto-Sterling A, Lauzanne K, Lee E. How sexually dimorphic are we? Review and synthesis. Am J Hum Biol. 2000;12(2):151-166. doi:10.1002/(SICI)1520-6300(200003/04)12:2<151::AID-AJHB1>3.0.CO;2-F.
- 5. Bermon S, Garnier PY, Hirschberg AL, et al. Serum Androgen Levels in Elite Female Athletes. J Clin Endocrinol Metab. 2014;99(11):4328-4335. doi:10.1210/jc.2014-1391
- 6. Women's Sports Foundation. Participation of Intersex Athletes in Women's Sports. www.WomensSportsFoundation.org•. Accessed September 1, 2018.
- 7. Romo V. IAAF Sets New Limits On Testosterone Levels In Women. NPR: The Two-Way. https://www.npr.org/sections/thetwo-way/2018/04/26/606039409/iaaf-sets-new-limits-on-testosterone-levels-in-women. Published 2018. Accessed September 1, 2018.
- 8. Monaco. IAAF Introduces New Eligibility Regulations for Female Classification.; 2018. https://www.iaaf.org/news/press-release/eligibility-regulations-for-female-classifica. Accessed September 2, 2018.
- 9. Bermon S, Garnier P-Y. Serum androgen levels and their relation to performance in track and field: mass spectrometry results from 2127 observations in male and female elite athletes. Br J Sports Med. 2017;51(17):1309-1314. doi:10.1136/bjsports-2017-097792
- 10. Pielke R, Tucker R, Boye E. Serious Problems Found in a Partial Replication of Bermon and Garnier (2017); 2018.
- 11. Sullivan CF. Gender Verification and Gender Policies in Elite Sport. J Sport Soc Issues. 2011;35(4):400-419. doi:10.1177/0193723511426293
- 12. Fryer B. Global Sports Community Joins Athlete Ally and Women's Sports Foundation in Calling on IAAF to Rescind Discriminatory Policy. Athlete Ally. https://www.athleteally.org/iaafopenletter/. Published 2018. Accessed September 2, 2018.
- 13. Longman J. Did Flawed Data Lead Track Astray on Testosterone in Women? The New York Times.
- https://www.nytimes.com/2018/07/12/sports/iaaf-caster-semenya.html. Published 2018. Accessed September 2, 2018. 14. Gerntholtz L, Worden M. RE: Eligibility Regulations for The Female Classification.; 2018. doi:10.1210/jc.2012-3893
- 15. Cumming M. Opposition to IAAF Classification. Toronto; 2018. https://www.caaws.ca/opposition-to-iaaf-classification/. Accessed September 19, 2018.
- 16. African News Agency. Sport Minister Calls for Opposition to New IAAF Regulations.; 2018.
- https://www.algoafm.co.za/article/domestic/93477/sport-minister-calls-for-opposition-to-new-iaaf-regulations-. Accessed September 19, 2018
- 17. Guth LM, Roth SM. Genetic influence on athletic performance. Curr Opin Pediatr. 2013;25(6):653-658. doi:10.1097/MOP.0b013e3283659087

Page 3 of 3

18. Schultz J. Caster Semenya and the "Question of Too": Sex Testing in Elite Women's Sport and the Issue of Advantage. Quest. 2011;63(2):228-243. doi:10.1080/00336297.2011.10483678

19. TUE Physician Guidelines Medical Information to Support the Decisions of TUE Committees. Male Hypogonadism.; 2018. https://www.wada-ama.org/sites/default/files/resources/files/hypogonadism_-_version_6.1_-_february_2018.pdf. Accessed September 1, 2018.

RELEVANT AMA POLICY

Blood Doping H-470.978

The AMA believes that a physician who participates in blood doping is deviating from his professional responsibility and that blood doping must be considered in the category of unnecessary medical services. Citation: (CEJA Rep B, I-85; Reaffirmed CLRPD Rep. 2, I-95; Reaffirmed: CSA Rep. 8, A-05; Reaffirmed: CSAPH Rep. 1, A-15

Surgical Modification of Female Genitalia H-525.987

Our AMA (1) encourages the appropriate obstetric/gynecologic and urologic societies in the United States to develop educational programs addressing medically unnecessary surgical modification of female genitalia, the many complications and possible corrective surgical procedures, and (2) opposes all forms of medically unnecessary surgical modification of female genitalia.

Citation: (Res. 13, A-91; Reaffirmed: Sunset Report, I-01; Reaffirmed: CEJA Rep. 8, A-11

Non-Therapeutic Use of Pharmacological Agents by Athletes H-470.994

Our AMA: (1) opposes the use of drugs for the purpose of enhancing athletic performance or sustaining athletic achievement. This action in no way should be construed as limiting a physician's proper use of drugs in indicated treatment of athletic injuries or clinical symptoms of individual athletes; and (2) endorses efforts by state level high school athletic associations to establish programs which include enforceable guidelines concerning weight and body fat changes on a precompetition basis for those sports in which weight management is a concern.

Citation: (Res. 89 part 2, A-72; Reaffirmed: CLRPD Rep. C, A-89; Modified by Res. 401, I-95; Reaffirmed: CSA Rep. 8, A-05; Reaffirmed: CSAPH Rep. 1, A-15

Conforming Birth Certificate Policies to Current Medical Standards for Transgender Patients H-65.967

- 1. Our AMA supports policies that allow for a change of sex designation on birth certificates for transgender individuals based upon verification by a physician (MD or DO) that the individual has undergone gender transition according to applicable medical standards of care.
- 2. Our AMA: (a) supports elimination of any requirement that individuals undergo gender affirmation surgery in order to change their sex designation on birth certificates and supports modernizing state vital statistics statutes to ensure accurate gender markers on birth certificates; and (b) supports that any change of sex designation on an individual's birth certificate not hinder access to medically appropriate preventive care.

Citation: (Res. 4, A-13; Appended: BOT Rep. 26, A-14

Resolution: 020

(A-19)

Introduced by: New Mexico

Subject: Request to the AMA Council on Ethical and Judicial Affairs (CEJA) to

Consider Specific Changes to the Code of Medical Ethics Opinion E-5.7, "Physician-Assisted Suicide", in Order to Remove Inherent Conflicts Within the Code, to Delete Pejorative, Stigmatizing Language, and to Adopt an

Ethical Position of Engaged Neutrality

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Our American Medical Association House of Delegates at the 2018 Interim Meeting rejected the recommendation in CEJA Report 2-I-18 that the Code of Medical Ethics Opinion E-5.7 "Physician-Assisted Suicide" (PAS) not be amended, and therefore did not adopt CEJA Report 2-I-18; and

6 Whereas.

- The Code of Medical Ethics Opinion E-5.7 1 states, 'Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks" – a characterization that clearly expresses the opinion that PAS is unethical; yet,
- The Code of Medical Ethics Opinion E-1.1.7 2 "Physician Exercise of Conscience" creates
 the clear understanding, not disputed by CEJA, that physicians participating in PAS are
 acting based on a thoughtful moral basis that is not outside the boundaries of ethical
 behavior; thereby,
- Creating an inherent contradiction within the Code of Medical Ethics: that physicians may ethically participate in something that is described as unethical; and

Whereas, It is important to recognize that ethical physicians can disagree, but that all perspectives be respected and none disparaged; and

Whereas, In addition to the inherent contradiction noted above, the decision that "the Code of Medical Ethics not be amended" is not consistent with the tenor of CEJA Report 2, and does not adequately address concerns about the implications of existing language in Opinion E-5.7; and

Whereas, The terms that stakeholders use to refer to the practice of physicians prescribing lethal medication to be self-administered by terminally ill patients reflect differing ethical perspectives, for the purposes of this resolution where existing language is not being cited, we have chosen to use "Physician-Assisted Dying" (PAD) as adopted by the American Academy of Hospice and Palliative Medicine³ as being much more consistent with the goal of being respectful and non-disparaging; and

Whereas, CEJA Report 2 cites a specific example of irreconcilable differences in principled core beliefs, but neglects to note that CEJA in that instance had very wisely adopted a nonjudgmental and non-stigmatizing approach that has served the profession well; and

4 5

7

8

9

10

1

2

3

11 12 13

16 17

14

15

22 23 24

25

26

27

28

29

20 21

30 31

Page 2 of 3

Whereas, PAD is a decision made by a competent adult about how, when, where and with whom to end life in the face of an irreversible terminal illness where continued living is not an option, and therefore is not equivalent to or appropriately described as "suicide", which can be most accurately defined as a decision by a person to take his or her own life rather than to continue living; and

Whereas, The American Association of Suicidology, in a treatise cited by CEJA¹², clearly states that, "Suicide and physician aid in dying are conceptually, medically, and legally different phenomena... the term 'physician-assisted suicide' in itself constitutes a critical reason why these distinct death categories are so often conflated, and should be deleted from use."; and

Whereas, Eight states and a federal district currently authorize PAD as an end-of-life option, making PAD available to 21% of Americans, and sixteen additional states have introduced legislation to enact it; and

Whereas, As determined by numerous polls and surveys, the overwhelming majority of the public, consistently over 70% ⁴, supports PAD; and

Whereas, National surveys^{5,6,7,8,11} of physicians demonstrate increasing support for PAD (from 46% in 2010 to 57% in 2016) and decreasing opposition to PAD (from 41% in 2010 to 29% in 2016); and

Whereas, Surveys of physicians conducted by the Colorado Medical Society ⁶, the Maryland State Medical Society ⁷, and the Massachusetts Medical Society ⁸ found majorities in support of PAD (56%, 54%, and 60% respectively); and

Whereas, There is no empirical evidence to substantiate the current description of PAD in Opinion E-5.7 as a form of abandonment "of a patient once it is determined that cure is impossible", and in fact CEJA acknowledges that PAD is also considered to be "an expression of care and compassion"; and

Whereas, Claims in the Code of Medical Ethics Opinion 5-7 that characterize PAD as "difficult or impossible to control", causing "more harm than good," and posing "serious societal risks", are unsubstantiated and speculative based on data reviews ⁹ cited in CEJA Report-2 that find conflicting interpretations but no definitive evidence to justify concerns for potential abuse; and

Whereas, It is widely acknowledged by patients, physicians and ethicists that suffering is not limited to physical pain, but equally includes emotional suffering due to loss of autonomy, and a loss of control over one's destiny while an opportunity for such control clearly exists, as evidenced by overwhelming attestations on the part of patients who have chosen the option of PAD as having a sense of enormous relief and comfort, even by patients who in the end never take the cocktail they've been prescribed; and

Whereas, "Engaged Neutrality"¹⁰ is a position that is neither "pro" nor "con", but allows for the expression of diverse views while ensuring safeguards and appropriate standards, educating the public, care givers and physicians, and protecting physicians' freedom to participate in or opt out of PAD according to their own personal values; therefore be it

Resolution: 020 (A-19) Page 3 of 3

RESOLVED, That our American Medical Association Council on Judicial and Ethical Affairs be strongly encouraged to remove from the Code of Medical Ethics Opinion E-5.7 "Physician-Assisted Suicide" judgmental, stigmatizing language that is not evidence based, is at odds with the conclusions of CEJA Report 2 in recognizing shared values of care, compassion, respect and dignity, and creates an ethical conflict with the Code of Medical Ethics Opinion E-1.1.7 "Physician Exercise of Conscience": specifically by:

7 8 9

10

11

12

13

14

15

16

17

18

19

20

21

22

- (a) Deleting all references to "suicide", including "Physician-assisted suicide" and replacing such language by referring to "Physician-assisted dying (PAD)";
- (b) Deleting language that suggests that PAD is a form of doing harm and is therefore antithetical to the admonition to "do no harm", such as "assisted suicide would ultimately cause more harm than good";
- (c) Deleting language that characterizes PAD as a choice by a patient "that death is preferable to life" and replacing that language with a description of PAD as giving a terminally ill patient the option of being in control of the manner of his or her death, without assigning a value judgment to that option;
- (d) Deleting language that characterizes PAD as "fundamentally incompatible with the physician's role as healer", and instead recognizing that a physician who participates in PAD is doing so as an act of compassion and caring for patients who have no prospect of healing their fatal illness;
- (e) Delete language that suggests that PAD is not compatible with "responding to the needs of patients at the end of life" or that PAD is "abandonment" (Directive to Take Action); and be it further

232425

26

27

28

29

30

31

32

33 34

35

36

RESOLVED, In recognition of the fact that highly ethical physicians may have differing opinions on Physician Assisted Dying (PAD), but also in recognition of our respect for patient autonomy and the growing numbers of patients who wish to exercise choice over the manner of imminent death, that our American Medical Association's Council on Judicial and Ethical Affairs (CEJA) be strongly encouraged to modify Code of Medical Ethics Opinion E-5.7 "Physicians-Assisted Suicide" to follow the lead of a number of state and national medical societies by adopting the ethical position of "Engaged Neutrality", defined as neither in favor of nor or in opposition to PAD, while providing reassurance that our AMA will be a resource to lawmakers, physicians and the public to ensure compliance with standards of lawful medical practice, and to protect physicians' freedom to participate or not participate in PAD in accordance with their personal beliefs and our AMA's Opinion E-1.1.7 "Physician Exercise of Conscience". (Directive to Take Action)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 05/09/19

¹ AMA Code of Medical Ethics, Opinion E-5.7, Physician-Assisted Suicide, https://tinyurl.com/y27hy743

² AMA Code of Medical Ethics, Opinion E-1.1.7, Physician Exercise of Conscience, https://tinyurl.com/y4odsvfm

³ Statement on Physician-Assisted Dying, AAHPM Board of Directors, Jun 24, 2016 https://tinyurl.com/y3e4fka7

⁴ 72% of Americans Support Medical Aid in Dying, Gallup Poll May 31, 2018 https://tinyurl.com/ycaon4zw

⁵ Medscape Ethics Report 2016: Life, Death, and Pain, Dec 23, 2016 https://tinyurl.com/y3u63b8c

⁶ Colorado Medical Society Member Survey, On Issues Surrounding Physician-Assisted Death, Feb 2016 https://tinyurl.com/y54b947y

⁷ MedChi Survey on Physician Assisted Suicide/Aid in Dying, June-July 2016 https://tinyurl.com/y5dl4plq

⁸ Massachusetts Medical Society (MMS) Survey on Medical Aid in Dying, August 2017 https://tinyurl.com/y34wqrrz

⁹ Battin MP, van der Heide A, Ganzini L, et al, Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups, Journal of Medical Ethics 2007;33:591-597 https://tinyurl.com/yxharp6k

¹⁰ Frye J, Youngner SJ. A Call for a Patient-Centered Response to Legalized Assisted Dying, Ann Intern Med. 2016;165:733–734. doi: 10.7326/M16-1319 https://tinyurl.com/yyzgmexo

¹¹ Assisted Death: Physician Support Continues to Grow, Medscape, Dec 2016 https://tinyurl.com/y3a6k2bl

¹² Statement of the American Association of Suicidology, Oct 2017: Suicide is not the same as "Physician Aid in Dying" https://tinyurl.com/yxholm6f

Resolution: 021

(A-19)

Introduced by: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont

Subject: Health, In All Its Dimensions, Is A Basic Human Right

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas In 1946, the World Health Organization (WHO) declared that the "enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being." Health is defined by the WHO as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." The constitution added that governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures The international community furthered the right to health movement in the 1948 United Nations Declaration of Human Rights.

7 8 9

2

4 5

6

Whereas, Presently, the United States is one of the only industrialized nations that doesn't provide universal access to health care;⁵ and

10 11 12

13

Whereas, United States citizens have a longstanding pattern of poorer health, and are dying at younger ages than people in almost all other "peer" countries, including other high-income democracies in western Europe, as well as Canada, Australia, and Japan; and

14 15 16

17

18

Whereas, The United States guarantees all citizens an education, access to fire and police services, a national postal service, protection by the military, a national park system, and many other federal- and state-funded services, but the country has not yet committed to ensuring that all of its citizens have health care in its many dimensions;⁷ and

19 20 21

22

23

Whereas, Social determinants of health (the conditions in which people are born, grow, live, learn, work, and age that affect a wide range of health and quality-of-life outcomes and risks) are widely recognized as a primary approach to reducing health disparities and have become a public health focus at the global, national, state, and local levels; 8,9,10 and

242526

27

Whereas, Numerous studies in recent decades have demonstrated the significant role nonmedical factors play in physical and mental health;¹¹and

¹ World Health Organization. Preamble to the Constitution of the World Health Organization. In: *Proceedings and Final Acts of the International Health Conference Held in New York from 19 June to 22 July 1946.* New York, NY: World Health Organization; 1948:100. *Official Records of the World Health Organization*:

² ld.

³ Constitution of the World Health Organization. https://www.who.int/governance/eb/who_constitution_en.pdf

⁴ United Nations. The Universal Declaration of Human Rights. http://www.un.org/en/documents/udhr/

⁵ Bauchner H. Health Care in the United States: A Right or a Privilege. JAMA. 2017;317(1):29. doi:10.1001/jama.2016.19687 ⁶ National Research Council (US); Institute of Medicine (US); Woolf SH, Aron L, editors. U.S. Health in International Perspective: Shorter Lives, Poorer Health. Washington (DC): National Academies Press (US); 2013. Available from:

https://www.ncbi.nlm.nih.gov/books/NBK115854/ doi: 10.17226/13497

⁷ JAMA. 2017;317(1):29. doi:10.1001/jama.2016.19687

⁸ https://www.cdc.gov/nchhstp/socialdeterminants/faq.html#c.

⁹ http://www.who.int/social_determinants/thecommission/en/.

¹⁰ https://www.cdc.gov/socialdeterminants/.

¹¹ http://annals.org/aim/fullarticle/2678505/addressing-social-determinants-improve- patient-care-promote-health-equity-american.

Resolution: 021 (A-19) Page 2 of 3

Whereas, Food insecurity, for example, is associated with increased risk for diseases and conditions like diabetes, hypertension, and depression in adults, and with increased risk for impaired brain development, hospitalizations, iron-deficiency anemia, mental health, and behavioral disorders in children; 12,13,14,15,16 and

Whereas, Housing insecurity and homelessness are related to poorer physical health, including higher rates of tuberculosis, hypertension, asthma, diabetes, and HIV/AIDS and higher rates of medical hospitalizations; and

Whereas, Blue Cross Blue Shield of Massachusetts Foundation noted that there is strong evidence that increased investment in selected social services as well as various models of partnership between health care and social services can confer substantial health benefits and reduce health care costs for targeted populations;¹⁷ and

Whereas, The social determinants of health play a key role in health outcomes and health disparities, and that addressing the social determinants of health for patients and communities is critical to the health of our patients, our communities, and a sustainable, effective health care system; and

Whereas, Planning the most effective strategy(s) to provide health care coverage in the United States is an evolving process, and will require careful evaluation, assessment, and modification; and

Whereas, The core principles to guide the envisioned future reforms and goals of health care have not been clearly stated; and

Whereas, Strategies to address future health care reforms and goals cannot be accomplished without stating and acknowledging the principles that will serve as the compass by which decisions will be made; and

Whereas, Physicians and medical societies should help define the principles upon which health care reforms and goals are structured and speak with a single voice and acknowledge that health is a basic right for every person in a just society, and not a privilege to be available and affordable only for a majority; and

Whereas, Physician members of the AMA rightfully focus on the provision of health care and its role in providing for the health of populations and a right to health care is only one aspect of a larger right to health;¹⁸ and

⁻

¹² Hunger and Health: The Impact of **Poverty**, Food Insecurity, and Poor Nutrition on Health and Well-Being. Food Research and Action Center (FRAC), 2017.

¹³ Hunger and Health: The Role of the Federal Child Nutrition Programs in Improving Health and Well-Being. Food Research and Action Center (FRAC). 2017.

^{14 8} Olsen CM. Nutrition and Health Outcomes Associated with Food Insecurity and Hunger. Journal of Nutrition. 1999;129(2):5215-5245.

¹⁵ Cook JT, Frank DA, Berkowitz C, Black MM, Casey PH, Cutts DB, et al. Food Insecurity is Associated with Adverse Health Outcomes among Human Infants and Toddlers. Journal of Nutrition. 2004;134(6):1432-1438.

¹⁶ Gundersen C, Ziliak JP. Food insecurity and health outcomes. Health Affairs. 2015;34(11):1830

¹⁷ https://bluecrossmafoundation.org/sites/default/files/download/publication/Social_Equity_ExecSumm_final.pdf.

¹⁸ World Health Organization. Preamble to the Constitution of the World Health

Resolution: 021 (A-19) Page 3 of 3

Whereas, In addition to health care, a right to health encompasses a right to provision of social
 measures including sufficient food and drinking water, adequate housing and working
 conditions, satisfactory education; ¹⁹ and

4 5

Whereas, Spending on social measures arguably has a greater aggregate impact on population health than medical care; 20 and

6 7 8

Whereas, The United States currently gives limited attention to social programs and continues to outspend its peers on medical care;²¹ and

9 10 11

Whereas, We as physicians share the professional responsibility to advocate for the health and well-being of our patients; and

12 13 14

Whereas, We as the AMA have consistently affirmed our common belief that comprehensive health care access should be available to all; and

15 16 17

18

Whereas, Principles to direct our AMA advocacy for patients should support a right to health, in all its dimensions (including addressing social determinants of health and universal access to timely, acceptable and affordable health care of appropriate quality care); and

19 20 21

Whereas, AMA policies on access to healthcare and its ongoing work and focus on social determinants of health and preventive care would benefit from core principles that support future advocacy and education; therefore be it

232425

22

RESOLVED, That our American Medical Association acknowledge that enjoyment of the highest attainable standard of health, in all its dimensions, including health care is a basic human right (New HOD Policy); and be it further

272829

30

26

RESOLVED, That the provision of health care services as well as optimizing the social determinants of health is an ethical obligation of a civil society. (New HOD Policy)

Fiscal Note: Not yet determined

Received: 05/09/19

¹⁹ United Nations. The Universal Declaration of Human Rights.

²⁰ K. Davis, K. Stremikis, C. Schoen, and D. Squires, Mirror, Mirror on the Wall, 2014 Update: How the U.S. Health Care System Compares Internationally, The Commonwealth Fund, June 2014.

https://www.commonwealthfund.org/publications/fund-reports/2014/jun/mirror-mirror-wall-2014-update-how-us-health-care-system ²¹ Bradley EH, Elkins BR, Herrin J, Elbel B. Health and social service expenditures: associations with health outcomes. BMJ Qual Saf. 2011;20(10):826-831.

Resolution: 022

(A-19)

Introduced by: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont

Subject: Opposition to Involuntary Civil Commitment for Substance Use Disorder

Reference Committee on Amendments to Constitution and Bylaws

(William Reha, MD, MBA, Chair)

Whereas, Involuntary civil commitment is defined by law as the commitment of a person who is ill, incompetent, drug-addicted, or the like, without the consent of the person being committed; and

Whereas, In response to the opioid crisis, the scope of these laws has rapidly expanded, as the number of states with such laws went from 18 in 1991 to 38 jurisdictions in 2016¹; and

Whereas, Existing data on both the short- and long-term outcomes following involuntary civil commitment for reasons related to substance-use disorder does not support its broad utilization²; and

Whereas, Data suggests that coercive treatment puts patients at higher risk of fatal overdose³; and

Whereas, The legal standards and procedures for involuntary civil commitment are very broad and allow for the presiding judge to overrule the clinical determination of the commitment's appropriateness; and

Whereas, Involuntary civil commitment of persons for reasons related to substance-use disorder has already been implicated in human rights abuses and suicides⁴; and

Whereas, Overdose data has shown that people who were involuntarily committed were more than twice as likely to experience a fatal overdose as those who completed voluntary treatment⁵; and

Whereas, Our AMA urges the formulation of a comprehensive national policy on drug abuse that should expand the availability and reduce the cost of treatment programs for substance use disorders, including addiction (H-95.981, "Federal Drug Policy in the United States"); and

Whereas, Our AMA urges expanding the quantity and improving the quality of drug treatment programs (H-95.973, "Increased Funding for Drug Treatment"); and

Whereas, Our AMA policy is that health promotion should be a collaborative, patient-centered process that promotes trust and recognizes patients self-directed roles and responsibilities in maintaining health (Code of Medical Ethics Opinion 8.11 Health Promotion and Preventive Care)⁶: therefore be it

Page 2 of 2

1 RESOLVED, That our American Medical Association oppose involuntary civil commitment

2 without judicial involvement of persons for reasons solely related to substance-use disorder

(New HOD Policy); and be it further

3

5 RESOLVED, That our AMA work to advance policy and programmatic efforts to address gaps in

6 voluntary substance-use treatment services. (Directive to Take Action)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 05/09/19

¹Involuntary Commitment For Individuals With A Substance Use Disorder Or Alcoholism, The National Alliance For Model State Drug Laws, 100 ½ E. Main Street, Manchester, Iowa 52057, © 2016 Research is current as of August 2016. Web/PDF http://www.namsdl.org/lssuesandEvents/NEW%20Involuntary%20Commitment%20for%20Individuals%20with%20a%20Substance%20Use%20Disorder%20or%20Alcoholism%20August%202016%2009092016.pdf

² Nature and Utilization of Civil Commitment for Substance Abuse in the United States, <u>J Am Acad Psychiatry Law 43:313–20, 2015</u> Web http://jaapl.org/content/43/3/313.long PDF http://jaapl.org/content/jaapl/43/3/313.full.pdf

³ An Assessment of Opioid Related Deaths in Massachusetts (2013-2014) https://www.mass.gov/files/documents/2016/09/pg/chapter-55-report.pdf

⁴Patients call Plymouth addiction center a mere jail - <u>The Boston Globe</u>

⁵https://www.mass.gov/service-details/chapter-55-overdose-report

⁶https://www.ama-assn.org/delivering-care/ethics/health-promotion-and-preventive-care