Reference Committee on Amendments to Constitution and Bylaws

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The Board of Trustees (BOT) and the Specialty and Service Society (SSS) considered the applications of the American Academy of Sleep Medicine and the American Society of Cytopathology for national medical specialty organization representation in the American Medical Association (AMA) House of Delegates (HOD). The applications were first reviewed by the AMA SSS Rules Committee and presented to the SSS Assembly for consideration.

Organizations seeking admission were asked to provide appropriate membership information to the AMA. That information was analyzed to determine AMA membership, as required under criterion 3. A summary of this information is attached to this report as Exhibit B.

In addition, organizations must submit a letter of application in a designated format. This format lists the above-mentioned guidelines followed by each organization’s explanation of how it meets each of the criteria.

Before a society is eligible for admission to the HOD, it must participate in the SSS for three years. Both organizations have actively participated in the SSS for more than three years.

Review of the materials and discussion during the SSS meeting at the 2018 Interim Meeting indicated that the American Academy of Sleep Medicine and the American Society of Cytopathology meet the criteria for representation in the HOD.

RECOMMENDATION

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.
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

<table>
<thead>
<tr>
<th>Organization</th>
<th>AMA Membership of Organization’s Total Eligible Membership</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Academy of Sleep Medicine</td>
<td>1,202 of 5,185 (23%)</td>
</tr>
<tr>
<td>American Society of Cytopathology</td>
<td>286 of 1,371 (21%)</td>
</tr>
</tbody>
</table>
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.
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.1 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.2

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). 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. 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. 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. Section 164.514(a) of the HIPAA Privacy Rule establishes standards for de-identifying 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 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.

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. 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).

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

- 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

- 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 de-
identified 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.1 For example, research using de-identified data
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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.

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),
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\(^2,^6\). 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).\(^7\) 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.\(^8\) 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.

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.\(^9\) 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.\(^10,^11\) 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.\(^12,^13\) 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.\(^14,^15,^16\) 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.\(^17\)

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.\(^18\) 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
motive for collecting their data during clinical encounters. In addition, patient record licensing 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, 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 de-identified 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.”28 Subscribers can voluntarily consent to allow their information to be used in research, and can also choose what level of de-identified 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.\(^2\)

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.\(^3\)

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.\(^4\) 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.\(^5\)

**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
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.

RECOMMENDATIONS

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

1. That our American Medical Association (AMA) reaffirm Policies H-315.974, “Guiding
   Principles, Collection and Warehousing of Electronic Medical Record Information,”
   Access to Patient Health Information,” H-315.978, “Privacy and Confidentiality,” and

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)

3. 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)

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

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.
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.
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.

DELEGATE REPRESENTATION

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.

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.

DELEGATION PRE-REGISTRATION/CREDENTIALING

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 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 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
Director of the Department of Veterans Affairs; the National Medical Association; the American Medical Women’s Association; the American Osteopathic Association; professional interest medical associations; and the AMA sections put the onus for certification on the president, secretary or other authorized individual. With respect to the regional medical student delegates and the delegates from the Resident and Fellow Section, the MSS or RFS chairs are responsible for certifying their respective delegates and alternate delegates, although the RFS bylaws further allow 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 initially credentialed as an alternate delegate (or substitute alternate delegate) to be recredential 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.

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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
provided under Bylaw 2.1.1.2. Only one constituent association from each U.S. state, commonwealth, territory, or possession shall be granted representation in the House of Delegates.

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2.1.4 Certification. The president or secretary of each constituent association or the president’s designee shall certify to the AMA the delegates and alternate delegates from their respective associations. Certification must occur at least 30 days prior to the Annual or Interim Meeting of the House of Delegates.

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2.2 National Medical Specialty Societies. The number of delegates representing national medical specialty societies shall equal the number of delegates representing the constituent societies. Each national medical specialty society 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 seat as may be provided under Bylaw 2.2.2. The total number of delegates apportioned to national medical specialty societies under Bylaw 2.2.1 shall be adjusted to be equal to the total number of delegates apportioned to constituent societies under sections 2.1.1 and 2.1.1.1.1 using methods specified in AMA policy.

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2.2.4 Certification. The president or secretary of each specialty society or the president’s designee shall certify to the AMA the delegates and alternate delegates from their respective societies. Certification must occur at least 30 days prior to the Annual or Interim Meeting of the House of Delegates.

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2.3 Medical Student Regional Delegates. In addition to the delegate and alternate delegate representing the Medical Student Section, regional medical student regional delegates and alternate delegates shall be apportioned and elected as provided in this bylaw. Medical student regional delegates and alternate delegates represent the constituent association that endorsed their candidacy pursuant to bylaw 2.3.3.

2.3.1 Qualifications. Medical student regional delegates and alternate delegates must be active medical student members of the AMA and attend medical school in the medical student region from which they seek election. In addition, medical student regional delegates and alternate delegates must be members of the constituent association in the state wherein their educational program is located.

2.3.1.1 Medical student regional alternate delegates may substitute for delegates in their same region in accordance with 2.8.5 and 2.10.4.

2.3.2 Apportionment. The total number of medical student regional delegates and alternate delegates is based on one delegate and one alternate delegate for each 2,000 active medical student members of the AMA, as recorded by the AMA on December 31 of each year. Each medical student region, as defined by the
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 medical student region.

2.3.3 Election. Medical Student regional delegates and alternate delegates shall be elected by the Medical Student Section in accordance with procedures adopted by the Section. Each elected delegate and alternate must receive written endorsement from the constituent association representing the jurisdiction within which the medical student’s educational program is located, in accordance with procedures adopted by the Medical Student Section and approved by the Board of Trustees. Delegates and alternate delegates shall be elected at the Business Meeting of the Medical Student Section prior to the Interim Meeting of the House of Delegates. Delegates and alternate delegates shall be seated at the Annual Meeting of the House of Delegates.

2.3.4 Certification. The Chair of the Medical Student Section Governing Council or the Chair’s designee shall certify to the AMA the delegates and alternate delegates for each medical student region. Certification of delegates and alternate delegates must occur at least 30 days prior to the Annual Meeting of the House of Delegates.

2.4 Delegates from the Resident and Fellow Section. In addition to the delegate and alternate delegate representing the Resident and Fellow Section, resident and fellow physician delegates and alternate delegates shall be apportioned and elected in a manner as provided in this bylaw.

2.4.1 Qualifications. Delegates and alternate delegates from the Resident and Fellow Section must be active members of the Resident and Fellow Section of the AMA. In addition, resident and fellow physician delegates and alternate delegates must be members of their endorsing constituent association, national medical specialty society, federal service or professional interest medical association.

2.4.2 Apportionment. The apportionment of delegates from the Resident and Fellow Section is one delegate for each 2,000 active resident and fellow physician members of the AMA, as recorded by the AMA on December 31 of each year.

2.4.3 Election. Delegates and alternate delegates shall be elected by the Resident and Fellow Section in accordance with procedures adopted by the Section. Each delegate and alternate delegate must receive written endorsement from his or her constituent association, or national medical specialty society, federal service or professional interest medical association in accordance with procedures adopted by the Resident and Fellow Section and approved by the Board of Trustees.

2.4.4 Certification. The Chair of the Resident and Fellow Section Governing Council or the Chair’s designee shall certify to the AMA the delegates and alternate delegates for the Resident and Fellow Section. Certification of delegates and alternate delegates must occur at least 30 days prior to the Annual Meeting of the House of Delegates.
2.6 **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.

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.

2.8 **Alternate Delegates.** Each organization represented in the House of Delegates may select an alternate delegate for each of its delegates entitled to be seated in the House of Delegates.

2.8.1 **Qualifications.** Alternate delegates must be active members of the AMA and of the entity they represent.

2.8.5 **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.

2.8.6 **Status.** The alternate delegate is not a “member of the House of Delegates” as that term is used in these Bylaws. Accordingly, analternate 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 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.

2.10 **Registration and Seating of Delegates.**

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
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
stating 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
alternate delegate at the discretion of each national medical specialty society and professional interest medical association with representation in the House of Delegates. Certification must occur at least 30 days prior to the Annual or Interim meeting of the House of Delegates.

2.10.67 **Representation.** No delegate or alternate delegate may be registered credentialed or seated at any meeting to represent more than one organization in the House of Delegates.

2.10.78 **Medical Student Seating.** Each medical student regional delegate shall be seated with the constituent association representing the jurisdiction within which such delegate’s educational program is located.

2.10.80 **Resident and Fellow Seating.** Each delegate from the Resident and Fellow Section shall be seated with the physician’s endorsing constituent association or specialty society, federal service or professional interest medical association. In the case where a delegate has been endorsed by multiple associations both a constituent association and specialty society, the delegate must choose, prior to the election, with which delegation the delegate wishes to be seated.
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.
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].

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-
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].

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 devalues 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 (E-9.3.1) and their responsibilities to impaired colleagues (E-9.3.2).

**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
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. Physicians at all stages of their professional lives need to 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.

To fulfill the ethical responsibility of competence, individual physicians and physicians in training should strive to:

(a) Cultivate continuous self-awareness and self-observation.
(b) Recognize that different points of transition in professional life can make different demands on competence.
(c) Take advantage of well-designed tools for self-assessment appropriate to their practice settings and patient populations.
(d) Seek feedback from peers and others.
(e) Be attentive to environmental and other factors that may compromise their ability to bring appropriate skills to the care of individual patients and act in the patient’s best interest.
(f) Intervene in a timely and appropriate manner when a colleague’s ability to practice safely is compromised by impairment, in keeping with ethics guidance on physicians’ responsibilities to impaired colleagues.

Medicine as a profession should continue to refine mechanisms for assessing knowledge and skill and should develop meaningful opportunities for physicians and physicians in training to hone their ability to be self-reflective and attentive in the moment.

(New HOD/CEJA Policy)

Fiscal Note: Less than $500.
REFERENCES


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.

“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 Principles of Medical Ethics, 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” (AMA Principles of Medical Ethics, 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.

Fiscal Note: None.

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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


27. Quill TE. Doctor, I want to die. will you help me? *JAMA* 1993;270:870–873.

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
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.
(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*
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.

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.

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:

• 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.

• 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.

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.

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1Reports 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.
2009 POLICIES

In this report, the Council on Ethical and Judicial Affairs (CEJA) presents its recommendations regarding the disposition of 2009 House policies that were assigned to or originated from CEJA.

DUPLICATIVE POLICIES

On the model of the Council on Long Range Planning & Development (CLRPD)/CEJA Joint Report I-01 and of subsequent reports of CEJA’s sunset review of House policies, this report recommends the rescission of House policies issued since June 2009. As noted previously, the intent of this process is the elimination of duplicative ethics policies from PolicyFinder. The process does not diminish the substance of AMA policy in any sense. Indeed, CEJA Opinions are a category of AMA policy.

MECHANISM TO ELIMINATE DUPLICATIVE ETHICS POLICIES

The Council continues to present reports to the HOD. If adopted, the recommendations of these reports continue to be recorded in PolicyFinder as House policy. After the corresponding CEJA Opinion is issued, CEJA utilizes its annual sunset report to rescind the duplicative House policy.

For example, at the 2007 Interim Meeting, the HOD adopted the recommendations of CEJA Report 8-I-07, “Pediatric Decision-Making.” It was recorded in PolicyFinder as Policy H-140.865. At the 2008 Annual Meeting, CEJA filed the corresponding Opinion E-2.026, thereby generating a duplicative policy. Under the mechanism to eliminate duplicative ethics policies, CEJA recommended the rescission of Policy H-140.865 as part of the Council’s 2009 sunset report.

The Appendix provides recommended actions and their rationale on House policies from 2009, as well as on duplicate policies.

RECOMMENDATION

The Council on Ethical and Judicial Affairs recommends that the House of Delegates policies that are listed in the Appendix to this report be acted upon in the manner indicated and the remainder of this report be filed. (Directive to Take Action)

Fiscal Note: Less than $500.
## APPENDIX - RECOMMENDED ACTIONS

<table>
<thead>
<tr>
<th>Policy No.</th>
<th>Title</th>
<th>Recommended Action &amp; Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>D-105.998</td>
<td>Direct to Consumer Advertising D-105.998</td>
<td>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.</td>
</tr>
<tr>
<td>D-250.991</td>
<td>Victims of the War in Kosovo</td>
<td>Rescind. Policy is outdated. The goal of this directive was originally accomplished by the establishment of the Physician Opportunities Portal, which has been discontinued.</td>
</tr>
<tr>
<td>D-250.992</td>
<td>Medical Supply Donations to Foreign Countries</td>
<td>Rescind. Policy is outdated and duplicates efforts of the World Health Organization, which provides up-to-date international information and guidelines on humanitarian donations of medical supplies at <a href="https://www.who.int/hac/crises/haiti/appeal/medical_supplies/en/">https://www.who.int/hac/crises/haiti/appeal/medical_supplies/en/</a>.</td>
</tr>
<tr>
<td>D-315.994</td>
<td>Abuse of the Medical Record for Regulation or Financing the Practice of Medicine</td>
<td>Rescind. The goal of this directive is accomplished through extensive materials available at <a href="https://www.ama-assn.org/search?search=confidentiality%2C+medical+records&amp;sort_by=search_api_relevance">https://www.ama-assn.org/search?search=confidentiality%2C+medical+records&amp;sort_by=search_api_relevance</a></td>
</tr>
<tr>
<td>D-315.996</td>
<td>Interim Report of the Inter-Council Task Force on Privacy and Confidentiality</td>
<td>Rescind. The goal of this directive is accomplished by extensive materials available at <a href="https://policysearch.ama-assn.org/policyfinder/search/HIPAA/relevant/1/">https://policysearch.ama-assn.org/policyfinder/search/HIPAA/relevant/1/</a></td>
</tr>
<tr>
<td>D-373.998</td>
<td>Guidelines for Handling Derogatory Conduct in the Patient-Physician Relationship</td>
<td>Rescind. The goal of this directive was accomplished in AMA correspondence to the Joint...</td>
</tr>
<tr>
<td>Code</td>
<td>Description</td>
<td>Action</td>
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</tr>
<tr>
<td>D-460.974</td>
<td>Office for Human Research Protections Interpretation of 45 CFR Part 46</td>
<td>Rescind</td>
</tr>
<tr>
<td>D-60.970</td>
<td>Disclosure of Health Status to Children and Adolescents</td>
<td>Rescind</td>
</tr>
<tr>
<td>D-70.954</td>
<td>Transition to ICD-10 Code Sets</td>
<td>Rescind</td>
</tr>
<tr>
<td>H-5.990</td>
<td>Policy on Abortion</td>
<td>Reaffirm</td>
</tr>
<tr>
<td>H-65.985</td>
<td>Inappropriate Federal Prosecution</td>
<td>Reaffirm</td>
</tr>
<tr>
<td>H-140.921</td>
<td>Preserving the Traditional Patient-Physician Relationship</td>
<td>Rescind</td>
</tr>
<tr>
<td>H-140.926</td>
<td>Policy for Physician Entrepreneur Activity</td>
<td>Reaffirm</td>
</tr>
<tr>
<td>H-140.949</td>
<td>Physician-Assisted Suicide</td>
<td>Rescind</td>
</tr>
</tbody>
</table>

Commission and directive is duplicative of **E-1.2.2**, 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.

The goal of this directive was accomplished in AMA correspondence with the Office of Human Research Protections and has been superseded by the revised Common Rule (2017).

This directive is outdated and is superseded by the revised Common Rule (2017).

The goal of this directive was accomplished by amendments to **E-2.1.1**, Pediatric Decision Making, adopted in 2010, 2018.

The goal of this directive is accomplished by extensive material available at [https://www.ama-assn.org/search?search=ICD-10](https://www.ama-assn.org/search?search=ICD-10).

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 (2010)

### AMA Policies on Professionalism

#### Professionalism and Medical Ethics H-140.951

The AMA reaffirms that the medical profession is solely responsible for establishing and maintaining standards of professional medical ethics and that the state cannot legislate ethical standards or excuse physicians from their ethical obligations; and urges all physicians and other appropriate health professional organizations to make their views known to their state legislatures and governors:

**Reaffirmation of Professionalism H-140.996**

Our AMA believes that the primary mission of the physician is to use his best efforts and skill in the care of his patients and to be mindful of those forces in society that would erode fundamental ethical medical practice. The AMA affirms that the medical profession is solely responsible for establishing and maintaining standards of professional medical ethics and that the state neither legislate ethical standards nor excuse physicians from their ethical obligations. The AMA House of Delegates, Board of Trustees, staff, and membership rededicate themselves to professionalism such that it permeates all activities and is the defining characteristic of the AMA's identity.

#### Readability of Medical Notices of Privacy Practices

Our AMA provides sample language for notice of privacy practices at
<table>
<thead>
<tr>
<th>H-315.997</th>
<th>Patients' Access to Information Contained in Medical Records</th>
<th>Rescind Policy is outdated. HIPAA mandates patient access to their medical records.</th>
</tr>
</thead>
<tbody>
<tr>
<td>H-315.998</td>
<td>Medical Record Privacy</td>
<td>Rescind. Policy adopted in 1979 is superseded by more recent law and regulation. AMA model legislation on this issue is no longer publicly available.</td>
</tr>
<tr>
<td>H-350.971</td>
<td>Initiatives Regarding Minorities</td>
<td>Defer recommendation to 2019 Interim meeting pending review by Chief Health Equity Officer. Consider consolidating these and other policies that address identified patient populations and health disparities:</td>
</tr>
<tr>
<td>H-350.975</td>
<td>Improving Healthcare of Hispanic Populations in the United States</td>
<td></td>
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</tbody>
</table>

- **H-160.991 Health Care Needs of Gay, Lesbian, Bisexual and Transgender Populations**
- **H-295.878 Eliminating Health Disparities—Promoting Awareness and Education of Lesbian, Gay, Bisexual and Transgender (LGBT) Issues in Medical Education**
- **H-350.957 Addressing Immigrant Health Disparities**
- **H-350.958 Hispanic Population and Access to the US Healthcare System**
- **H-350.959 Guiding Principles for Eliminating Racial and Ethnic Health Care Disparities**
- **H-350.961 Improving the Health of Minority Populations**
- **H-350.966 Health Initiatives on Asian-Americans and Pacific Islanders**
<table>
<thead>
<tr>
<th>Section Code</th>
<th>Description</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>H-350.971</td>
<td>AMA Initiatives Regarding Minorities</td>
<td></td>
</tr>
<tr>
<td>H-350.972</td>
<td>Improving the Health of Black and Minority Populations</td>
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<tr>
<td>H-350.974</td>
<td>Racial and Ethnic Disparities in Health Care</td>
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</tr>
<tr>
<td>H-350.976</td>
<td>Improving Health Care of American Indians</td>
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</tr>
<tr>
<td>H-440.869</td>
<td>Establishment of State Commission/Task Force to Eliminate Racial and Ethnic Health Care Disparities</td>
<td></td>
</tr>
<tr>
<td>D-350.996</td>
<td>Strategies for Eliminating Minority Health Care Disparities</td>
<td></td>
</tr>
<tr>
<td>D-55.997</td>
<td>Cancer and Health Care Disparities among Minority Women</td>
<td></td>
</tr>
<tr>
<td>D-65.995</td>
<td>Health Care Disparities among Gay, Lesbian, Bisexual and Transgender Families</td>
<td></td>
</tr>
<tr>
<td>H-515.967</td>
<td>Protection of the Privacy of Sexual Assault Victims</td>
<td>Reaffirm</td>
</tr>
</tbody>
</table>
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 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.
(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.


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

Received: 03/20/19
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
References:

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
Whereas, The current US population of transgender adults is estimated to be about 0.6% of the US population, or about 1.4 million adults; 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 identity; 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 assaulted; 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 records; 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 transition; 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); 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, California, District of Columbia, Idaho, Massachusetts, Minnesota, Montana, Nevada, New Jersey, New York City, Oregon, and Washington; 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, Colorado, Connecticut, District of Columbia, Maine, Minnesota, Nevada, New Jersey, New York City, Oregon, Arkansas, and Washington; and
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:

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
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.

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: 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

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
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. (Directive to Take Action)

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

Received: 04/25/19
Whereas, A small but significant number of individuals have gender identities that differ from their genotypic and phenotypic gender; and

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

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

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

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

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
Whereas, Communication is one of the foundational aspects of patient care that impacts patient satisfaction and builds rapport between a physician and patient; 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, encourage a healthy relationship between researchers and the community, and may reduce stigma associated with certain disease states; 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; 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; 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; 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
RESOLVED, That our American Medical Association encourage the use of person-centered language. (New HOD Policy)

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

Received: 05/01/19

References:

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.
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)
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 consent; 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
RESOLVED, That our AMA study the implications of the *Shinal v. Toms* ruling and its potential effects on the informed consent process. (Directive to Take Action)

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

Received: 05/01/19

References:

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
(1) 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