Reference Committee on Amendments to Constitution and Bylaws

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017# Revised Mission Statement of the AMA

# Contained in the Handbook Addendum
Subject: New Specialty Organizations Representation in the House of Delegates

Presented by: Gerald E. Harmon, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Peter H. Rheinstein, MD, JD, MS, Chair)

The Board of Trustees (BOT) and the Specialty and Service Society (SSS) considered the applications of the American Rhinologic Society, American Society for Reconstructive Microsurgery, American Society of Neuroimaging, North American Neuromodulation Society, and the North American Neuro-Ophthalmology Society 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.

The applications were considered using criteria developed by the Council on Long Range Planning and Development and adopted by the HOD (Policy G-600.020). (Exhibit A)

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. All five organizations have actively participated in the SSS for more than three years.


RECOMMENDATION

Therefore, the Board of Trustees recommends that the American Rhinologic Society, American Society for Reconstructive Microsurgery, American Society of Neuroimaging, North American Neuromodulation Society, and the North American Neuro-Ophthalmology Society 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
GUIDELINES FOR REPRESENTATION IN & ADMISSION TO
THE HOUSE OF DELEGATES:

**National 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 Rhinologic Society</td>
<td>172 of 265 (65%)</td>
</tr>
<tr>
<td>American Society for Reconstructive Microsurgery</td>
<td>168 of 663 (25%)</td>
</tr>
<tr>
<td>American Society of Neuroimaging</td>
<td>105 of 280 (38%)</td>
</tr>
<tr>
<td>North American Neuromodulation Society</td>
<td>260 of 942 (28%)</td>
</tr>
<tr>
<td>North American Neuro-Ophthalmology Society</td>
<td>100 of 454 (22%)</td>
</tr>
</tbody>
</table>
REPORT OF THE BOARD OF TRUSTEES

BOT Report 13-A-18

Subject: Mergers of Secular and Religiously Affiliated Health Care Institutions and Their Impact on Patient Care and Access to Services

Presented by: Gerald E. Harmon, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws (Peter H. Rheinstein, MD, JD, MS, Chair)

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Policy D-140.956, “Religiously Affiliated Medical Facilities and the Impact on a Physician's Ability to Provide Patient Centered, Safe Care Services,” asks that the American Medical Association (AMA):

- conduct a study of access to care in secular hospitals and religiously affiliated hospitals to include any impact on access to services of consolidation in secular hospital systems and religiously affiliated hospital systems.

AMA lacks the necessary research infrastructure to carry out an extensive empirical study regarding the impact of such mergers on patients’ access to care. This report reviews the best evidence currently available in this area from governmental agencies, academic institutions, and scholarly and popular publications. Council on Ethical and Judicial Affairs Report 2-A-18, “Mergers of Secular and Religiously Affiliated Health Care Institutions,” provides ethics guidance for physicians in this context.

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BACKGROUND

The changing landscape of the American healthcare sector and evolving market forces have motivated health care institutions to consider mergers, acquisitions, partnerships, and other types of transactional relationships for the purpose of consolidation [1]. The economic recession from 2007 to 2009 and the passage of the 2010 Affordable Care Act (ACA) may have played a substantial role in driving mergers in recent years; 112 mergers were reported in 2015, compared to 105 in 2012 and 66 in 2010 [1,3]. With the ACA encouraging the creation of Accountable Care Organizations for coordinated care and new value-based payment models, health care institutions were encouraged to merge and create economies of scale to reduce expenses and share profits across larger patient volumes, standardize and streamline protocols to improve operational efficiency, and expand their scope of services and care networks to facilitate patient access [3–5].

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RELIGIOUSLY AFFILIATED HEALTHCARE IN THE UNITED STATES

Secular and religiously affiliated institutions alike feel pressures to merge [6], in particular, small, independent, rural, and/or financially struggling hospitals [7]. Rural populations often face wide health disparities and lack of access to care, and over 2,000 rural hospitals struggle operationally and financially with low patient volume, provider shortages, and poor facilities and resources [8]. Since 2010, more than 60 rural hospitals have closed in 20 states, and several hundred more may be
vulnerable to closure, especially in southern states [9]. Because of these issues, rural hospitals may be particularly susceptible to external and economic forces that lead them into merger transactions.

Religiously affiliated or faith-based health care institutions can include hospitals, clinics, and other centers of care partnered with, established by, owned by, and/or managed by a wide array of religious entities in the U.S., such as Catholic, Protestant (e.g., Methodist, Presbyterian, Baptist, Evangelical, Adventist), Mormon, and Jewish organizations. Catholic institutions are the most numerous, comprising over 600 hospitals and over 1,600 clinics and other care facilities [10]. Collectively, they serve as the nation’s largest group of nonprofit health care providers [10,11]. Catholic hospitals constitute nearly 15 percent of all acute care hospitals, treating about one-sixth of all acute care hospital patients, with 5 million admissions and 20 million emergency room visits a year [10]. Since 1997, over 140 mergers have occurred between non-Catholic and Catholic institutions [12]. From 2000 to 2016, the number of acute care hospitals with Catholic affiliations grew 22 percent, even as the overall number of acute care hospitals declined [11]. Ten of the 25 largest health systems are Catholic-affiliated [11]. An estimated 25 percent of Catholic hospitals and 15 percent of Catholic continuing care facilities are located in rural areas [10]. Out of over 1,300 Critical Access Hospitals (specially designated hospitals located in high-need rural areas), 132 are Catholic-affiliated [10,13]; as of 2016, 46 Catholic hospitals were the sole health providers for their communities [11].

Protestant and Jewish institutions also form a prominent part of the religiously affiliated healthcare sector. In the U.S., around 50 hospitals and health systems are affiliated with the United Methodist Church; the Adventist Health System manages 46 facilities; and close to 20 Jewish hospitals are in operation; accurate figures are difficult to find for the numbers of Presbyterian, Baptist, Mormon, or other health care institutions [14,15,16].

THE IMPACT OF MERGERS ON PATIENT CARE

Evidence about the impact of mergers between secular and religiously affiliated institutions is limited and largely anecdotal in nature. Much of our knowledge of these issues is derived from news articles and reports from advocacy organizations such as the American Civil Liberties Union (ACLU) and MergerWatch.

Based on what evidence we have the effects on clinical services and care of mergers that involve non-Catholic religiously affiliated institutions appear to be diverse. For example, some Baptist, Adventist, and Mormon institutions are opposed to abortions in accordance with their principles [1,2]; other merged entities, such as Missouri’s Barnes-Jewish Hospital, and the Protestant-affiliated Advocate Health Care in Illinois do provide abortions [17,18,19]. (An institution’s faith tradition may shape nonclinical aspects of patient experience, as when Jewish hospitals observe Shabbat and Jewish holidays, display ritual objects, provide kosher meals, or designate kitchens for Orthodox patients [20]. Similarly, at least one Adventist institution declines to serve nonvegetarian food or any stimulants [21,22].)

Not surprisingly given the prominence of Catholic institutions in U.S. health care, the published material focuses heavily on mergers that involve Catholic organizations, which are governed by the Ethical and Religious Directives for Catholic Health Services (ERDs) issued by the U.S. Conference of Catholic Bishops [23]. The ERDs address many aspects of institutional life in Catholic and Catholic-affiliated facilities, providing directives not only regarding the services available to patients, but also directives to guide partnerships between Catholic and non-Catholic health care institutions [23]. Other faith-based health care organizations do not have a comparable
Religious Directives for Catholic Health Services

The Catholic Health Association of the United States (CHA) identifies its member institutions as ministries of the Catholic Church [24]. In line with the religious values of the Church and the guidance of the ERDs, Catholic institutions often restrict the provision of certain health services, particularly in reproductive care [11,23]. The ERDs state that “abortion…is never permitted,” although “operations, treatments, and medications that have as their direct purpose the cure of a proportionately serious pathological condition of a pregnant woman are permitted when they cannot be safely postponed until the unborn child is viable” [23]. Additionally, Catholic institutions “may not promote or condone contraceptive practices,” and “direct sterilization of either men or women, whether permanent or temporary, is not permitted” [23].

Reproductive Health Services. Women have been denied a wide range of reproductive services at Catholic hospitals, even when there may be substantial risk to the woman’s health or life of the patient [25–28]. Women with nonviable pregnancies have reportedly been turned away from Catholic hospitals until severe hemorrhaging or infection occurs [29]. In other cases, patients who request tubal ligations to be performed at the same time as a C-section are refused this service, even if future pregnancies are risky [29]. Obstetrician-gynecologists have also reported feeling unduly constrained by Catholic hospital administrators when exercising their clinical judgment in managing miscarriage, nonviable pregnancies, and serious maternal complications [30–32]; in one sample, 52 percent of obstetricians-gynecologists in Catholic institutions reported experiencing conflict with their hospital’s religious policies [32].

In 2010 in rural Arizona, the secular Sierra Vista Regional Health Center became affiliated with the Catholic-based Carondelet Health Network and adopted the ERDs to guide its clinical services [25]. In one incident at Sierra Vista, a physician is reported to have recommended termination of pregnancy to a woman who had miscarried one of her twins and faced a low chance of the other twin’s survival and high risk of hemorrhage and infection. A hospital administrator denied the procedure; however, and the patient was instead driven by ambulance to a hospital 80 miles away for treatment. After the incident, Sierra Vista broke their relationship with Carondelet after one year of a two-year trial period and chose to affiliate with a secular network instead.

Patients have also reported being unaware that the services they want will not be provided until they have already arrived at a Catholic hospital or begun treatment, and religious facilities can be unwilling to refer patients elsewhere [26,29].

This is not to say that Catholic facilities always adhere strictly or uniformly to the ERDs. For example, under the ERDs, men could also be refused many reproductive services, including contraception, sterilization, and participation in decisions on prenatal diagnosis and artificial insemination [23]; however, at least one Catholic health system, Ascension Health, performs vasectomies for men but not tubal ligations for women [33]. In 2010, Sister Margaret McBride, an administrator at a Catholic Healthcare West hospital in Arizona, authorized the termination of a pregnancy due to the high risk of mortality for both mother and child [33]. Although both the CHA and the hospital supported McBride’s decision, the local diocesan bishop later excommunicated McBride and stripped the hospital of its Catholic affiliation, causing controversy in the Catholic health community [34].
Services for Transgender Patients. The CHA does not specifically deny services on the basis of sexual orientation. In January 2018, Sister Carol Keehan, president and CEO of the CHA, stated that “any services [that Catholic institutions] offer are available to everybody,” elaborating that “transgender patients have heart attacks … and gallbladder surgery” and that “[Catholic hospitals] have delivered many a lesbian couple’s baby and many a gay couple’s baby” [35]. The Human Rights Campaign’s Healthcare Equality Index evaluates nearly 600 American hospitals on the basis of their care, services, and policies relating to LGBTQ individuals and has previously rated several Bon Secours hospitals, which are members of the CHA, with moderate to high scores [36].

However, Catholic institutions have refused to perform gender-affirming surgery in the past; in one example, Franciscan Health in Indiana sued the Obama administration over a gender identity nondiscrimination rule mandated by the ACA [37]. The National Catholic Bioethics Center believes that “no Catholic health care organization should require its personnel to carry out, promote, refer for, or otherwise cooperate formally in procedures involved in gender transitioning, especially surgical or hormonal intervention” [38]. In 2017, the CHA’s senior director of ethics and theology stated, “For most medical providers the issue is settled in terms of seeing gender dysphoria as something that can be treated legitimately…[but] Catholic ethicists still have many questions about its moral permissibility” [39]. There have been media reports of instances in which transgender patients have been denied hysterectomies under the ERD restriction on sterilization [40,41] and mastectomies [42–44].

Physician-Assisted Suicide. In U.S. jurisdictions that have legalized physician-assisted suicide—as of March 2018, California, Colorado, the District of Columbia, Hawaii, Montana, Oregon, Vermont, and Washington—access to legally permitted “aid in dying” is unlikely to be available from religiously affiliated institutions and clearly will not be from Catholic-affiliated institutions. In guidance on care for patients who are seriously ill or dying, the ERDs unequivocally prohibit intentionally hastening death, stating “Suicide and euthanasia are never morally acceptable options” [23]. The ERDs provide that “Catholic health care institutions may never condone or participate in euthanasia or assisted suicide in any way” [23].

The possible impact of these or similar restrictions is difficult to estimate, but reports indicate that the ERDs have had an effect in jurisdictions where physician-assisted suicide is legal. For example, in Washington state in 2010, the Catholic-affiliated PeaceHealth merged with the Clark County public hospital, which then stopped referring patients for PAS-related counseling [45]. In 2013, physicians at Harrison Medical Center in Bremerton, Washington, were restricted from prescribing medications for assisted suicide after Harrison affiliated with the Catholic-based Franciscan Health System [46]. As of 2012, some 30 percent of hospital beds in Washington were owned by Catholic institutions [47].

Effects on Health Plans

There is also evidence to suggest that mergers among secular and religiously affiliated health care institutions can affect the terms of health insurance plans. In 2017 in northwestern Indiana, for example, a proposed merger between a Catholic-affiliated Franciscan system and Methodist Hospitals would have left only one non-Catholic hospital in the county [37]. This hospital would not be included in the network of the only insurer offering plans for the region on the ACA exchange, in effect making Franciscan Health and Catholic hospitals exclusive providers for this plan. This may have forced patients on this plan to travel out of their network to receive services not provided by in-network facilities [37]. Some large Catholic health systems, such as Catholic Health Initiatives and Ascension Health, have also expressed interest in offering their own health insurance plans as they have expanded their merged systems [37]. Catholic institutions attaining
exclusive provider status with insurance plans, especially those offered by employers or on subsidized ACA exchanges, could create serious concerns for patient access to care.

CONCLUSION

Although there has been limited scholarly research regarding the clinical impact specifically of mergers among secular and religiously affiliated health care institutions, this literature suggests that patients may have more difficulty gaining access to some services as a result of such mergers. A growing body of anecdotal evidence in the form of media reports describing cases in which these mergers appear to have affected care for individual patients argues to a similar conclusion, as do efforts to monitor the impact of mergers among advocacy organizations.

RECOMMENDATION

Your Board of Trustees concludes that the foregoing fulfills Directive D-140.956, “Religiously Affiliated Medical Facilities and the Impact on a Physician's Ability to Provide Patient Centered, Safe Care Services,” and recommends that the directive be rescinded and the remainder of this report be filed. (Directive to take Action)

Fiscal Note: Less than $500
REFERENCES


INTRODUCTION

At the 2017 Annual Meeting, the House of Delegates referred Resolution 7-A-17, “Health Care as a Human Right.” This resolution was introduced by the Minority Affairs Section and asked that our AMA:

1. recognize that a basic level of health care is a fundamental human right;
2. support the United Nations’ Universal Declaration of Human Rights and its encompassing International Bill of Rights as guiding principles fundamental to the betterment of public health; and
3. advocate for the United States to remain a member of the World Health Organization.

HEALTH CARE AS A HUMAN RIGHT

Human rights are ethical demands that create duty to safeguard underlying freedoms of significant social importance. This duty may be legal, e.g., through statute or international treaty, or moral in its foundation. Depending on context, human rights can be thought of as legal, philosophical, or sometimes aspirational. All these concepts of human rights are interrelated; indeed, human rights are conceived through ethical reasoning drawing on experience, beliefs, and theories of justice.

The philosophical underpinning of creating an ethical human right is largely that of justice, which may be described as fairness in equitable distribution of primary social goods such as liberty, opportunity, and income. From this concept of fairness comes the ethical demand to create a human right, which may then be extended to health care, because by keeping people healthy, people’s ability to participate in political, social, and economic life is promoted and preserved. A right to health care does not give individuals a basic right either to be healthy or to have all their health care needs met.

However, a right to health care will broadly encompass access to care. Access means that health care facilities, goods, and services must be available to everyone in [a defined] jurisdiction without discrimination, [and must be] affordable, physically accessible, and within a reasonable distance for all people. If people are denied access to a basic level of services adequate to protect normal functioning, an injustice is done to them. Indeed, the concept of accessibility as a core principle of human rights to health care is widely recognized and supported.
Although it does not directly support a “right to health care,” Principle IX of the AMA Principles of Medical Ethics states: “A physician shall support access to medical care for all people.” Equitable access to medical care is a core component of the right to health care, and Opinion 11.1.1, of the Code of Medical Ethics, “Defining Basic Health Care,” is derived from this principle. The Opinion maintains that health care is “a fundamental human good because it affects our opportunity to pursue life goals, reduces our pain and suffering, helps prevent premature loss of life, and provides information needed to plan for our lives. Society has an obligation to make access to an adequate level of care available to all its members, regardless of ability to pay.” Further, Opinion 11.1.4, “Financial Barriers to Health Care Access,” explains: “As professionals, physicians individually and collectively have an ethical responsibility to ensure that all persons have access to needed care regardless of their economic means.”

Other policies of the AMA House of Delegates also support access to healthcare. For example, it is AMA policy that “no one shall be denied necessary medical care because of inability to pay for that care” (Policy H-160.987, “Access to Medical Care”). Policy H-160.975, “Planning and Delivery of Health Care Services,” explains that “both the public and private sectors should be encouraged to donate resources to improve access to health care services. Where appropriate, incentives should be provided for those in the private sector who give care to those who otherwise would not have access to such care. In addition, existing shortcomings in the current public system for providing access need to be addressed.”

SUPPORTING THE UNITED NATIONS’ DECLARATION OF HUMAN RIGHTS AND THE WORLD HEALTH ORGANIZATION

Resolution 7-A-17 also asks that our AMA support the United Nations’ Universal Declaration of Human Rights and the International Bill of Rights as guiding principles fundamental to the betterment of public health. The Declaration consists of 30 articles affirming an individual’s rights that, although not legally binding in themselves, have been elaborated in subsequent international treaties, economic transfers, regional human rights instruments, national constitutions, and other laws. The Declaration was the first step in the process of formulating the International Bill of Human Rights, which was completed in 1966, and came into force in 1976.

The United Nations (UN) is an intergovernmental organization made up of 193 member nations. The World Health Organization (WHO) is the directing and coordinating authority on international health within the UN system. The objective of WHO is the attainment by all peoples of the highest possible level of health. Governance takes place through the World Health Assembly (WHA), which is made up of representatives from the health ministries of these national governments, and is the supreme decision-making body. The Executive Board gives effect to the decisions and policies of the Health Assembly. The organization is headed by the Director-General, who is appointed by the WHA on the nomination of the Executive Board. The WHO collaborates with the UN system to position health in the debates and decisions of UN intergovernmental bodies; contributes to a coherent and effective UN system at global, regional, and country levels; provides leadership in health-related humanitarian efforts, and promotes alliances and interagency approaches to address health issues.

By contrast, the WMA is a non-governmental international organization representing physicians. The organization was created to ensure the independence of physicians and to work for the highest possible standards of ethical behavior and care by physicians at all times. The AMA is a founding member of the WMA, which has always been an independent confederation of free professional
associations and has grown to include 114 national medical association members. Our main role at
the WMA is to develop policy and advocacy agendas in line with AMA policies.

The WMA is in “Official Relations” with the WHO and seeks to advise and influence the work of
this intergovernmental body. WMA’s cooperation with the WHO is very broad and covers nearly
all areas of medicine and health. As a commitment to our international interests, AMA officers
have regularly attended the WHA, either as non-governmental advisors to the United States
Delegation or as Delegates to the Assembly from the WMA.

AMA Policy H-250.986, “AMA and Public Health in Developing Countries,” outlines a
circumscribed strategy for AMA participation in international policy and advocacy issues mainly
by our involvement in the WMA and, to a lesser degree, in our advisory capacity at the WHA. For
this and other reasons, our AMA does not take positions on treaties, such as the United Nations’
Universal Declaration of Human Rights, but works through established channels to effect
supportable outcomes.

In addition, AMA Policy H-250.999, “World Health Organization,” expresses AMA’s direct
support of the WHO as an institution and the United States’ involvement with it; this support is
ongoing. AMA Policy H-250.992, “World Health Organization,” affirms support for the WHO and
urges the United States to provide full funding for the organization. This policy also encourages the
WMA to develop cooperative work plans with the WHO.

CONCLUSION

The Board of Trustees appreciates that Resolution 7-A-17 expresses the desire to ensure that all
people have access to a basic level of health care. Our AMA has long advocated for equitable
access to health care through policy, advocacy, and a targeted strategy of active international
policymaking through the WMA and the WHO. The Board of Trustees believes that existing policy
adequately supports that intention.

RECOMMENDATION

The Board of Trustees therefore recommends that AMA Policies H-160.987, “Access to Medical
Care;” H-160.975, “Planning and Delivery of Health Care Services;” H-250.986, “AMA and
Public Health in Developing Countries;” H-250.992, “World Health Organization;” and
H-250.999, “World Health Organization,” be reaffirmed in lieu of Resolution 7-A-17 and that the
remainder of the report be filed. (Reaffirm HOD Policy)

Fiscal Note: Less than $500

REFERENCES

2 Gostin LO. Public Health, Ethics, and Human Rights: A tribute to the late Jonathan Mann. The Journal of
Law, Medicine & Ethics. 2001; 29:121-130.
338.
5 Kinney ED. The International Human Right to Health: What Does This Mean for our Nation and World?
6 McGill M, MacNaughton G. The Struggle to Achieve the Human Right to Health Care in the United States.
Subject: Appropriate Placement of Transgender Prisoners (Resolution 15-A-17)

Presented by: Gerald E. Harmon, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Peter H. Rheinstein, MD, JD, MS, Chair)

At the 2017 Annual Meeting the AMA House of Delegates referred Resolution 15-A-17, “Appropriate Placement of Transgender Prisoners,” from the New England delegation, which asked:

That our American Medical Association establish policy supporting the ability of transgender prisoners to be placed in facilities that are reflective of their affirmed gender status regardless of surgical status, if they so choose.

The Reference Committee on Amendments to Constitution and Bylaws noted that testimony was evenly divided in support of the resolution and ultimately recommended referral, recognizing the “complexities of this issue” and “that more information and research on the subject are necessary.” In response, this report identifies and addresses concerns relevant to the placement of transgender prisoners.

BACKGROUND

The problem facing the safety and health of transgender prisoners is severe and well documented. Transgender prisoners are disproportionately the victims of sexual assault, suffering higher rates of sexual assault than general population inmates [1,2]. The increased rate of violence largely stems from transgender prisoners being housed based on their birth sex, and not according to their affirmed gender [1]. One study showed that birth sex-based housing policy has allowed transgender prisoners to suffer from rape, harassment, and physical violence at a rate of 34 percent compared to 10 percent for the overall population [3]. Another study, of only California prisons, has shown that 59 percent of transgender prisoners experience sexual assault, versus only 4.4 percent of the overall prison population [4], with another study showing that the proportion of transgender prisoners in California experiencing sexual assault to be as high as 75 percent [1].

The risks of violence typically are in the context of transfeminine inmates, because “of animosity toward the expression of their gender identity and because many have slight and effeminate builds” [5]. Genitalia-based prison housing policies place transgender inmates at special risk of sexual violence, because the “prison hierarchy subjugates the weak to the strong and equates femininity with weakness” [6].

GENITALIA/BIRTH SEX-BASED HOUSING POLICY

The status quo of most prisons and jails in the United States is to house transgender prisoners according to their birth/biological sex and not according to their affirmed gender identity [7].
Genitalia based housing policy is “deeply ingrained” in the United States to the point where it is taken for granted without any official justification [8]. This status quo is founded on a limited definition of “transgender” constrained to the “gender binary,” a social construct where only two genders are recognized at birth: male or female [7,9]. A more useful definition of “transgender,” one that breaks free of the “gender binary,” is a person “whose inner gender identity and outward gender expression differ from the physical characteristics of the body at birth” [10].

Under the status quo, many correctional institutions try to ameliorate the risks and hazards of sex-based housing by placing transgender prisoners in administrative segregation. Such segregation, in the interests of safety, isolates transgender prisoners from the general population [1]. However, administrative segregation is not a good solution as it creates its own sets of problems. It often differs little from punitive segregation or solitary confinement. Such confinement removes prisoners from the companionship of others, denies prisoners access to prison programs, and is psychologically damaging [7]. Administrative segregation acts as a further punishment of the transgender prisoner and has been significantly criticized by scholars and attorneys [2].

ALTERNATIVE HOUSING POLICIES

In an attempt to address health and safety problems of transgender prisoners several jurisdictions have created alternative jail housing policies based on “the sex the individual identifies with and where they will be the safest, as opposed to genitalia-based placement” [9].

For example, in 2002 San Francisco County, California, instituted a protocol that requires jail officials to assess transgender prisoners for vulnerability and place vulnerable individuals in a unit with other vulnerable populations, away from “predators;” the policy has resulted in marked decreases in sexual assaults [2]. In 2009 the Washington, DC, Department of Corrections similarly enacted a housing policy that takes into account the opinions of transgender individuals and healthcare professionals and permits inmates to be housed according to their gender identity [9,11]. In 2011 Cook County, Illinois, likewise changed its policy to allow transgender inmates to “be housed, dressed, and searched according to their gender identity rather than the sex/gender they were assigned at birth” [9].

AMA POLICY

Several AMA policies address a range of transgender issues [12,13,14]. House Policy H-65.964, “Access to Basic Human Services for Transgender Individuals,” opposes policies that prevent transgender individuals from accessing services and facilities (including restrooms) in line with one’s gender identity [12]. House Policy H-65.967, “Conforming Birth Certificate Policies to Current Medical Standards for Transgender Patients,” supports policies that allow for a change of sex designation on a birth certificate for transgender individuals, whether or not an individual has undergone surgery [13]. House Policy H-40.966, “Military Medical Policies Affecting Transgender Individuals,” affirms that there is no medical reason to prohibit transgender individuals from serving in the military [14].
RECOMMENDATION

In consideration of evidence indicating the risk placement choices pose for transgender prisoners
the Board of Trustees recommends that the following be adopted in lieu of Resolution 15-A-17 and
the remainder of this report be filed:

1. That our American Medical Association 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 prisoner’s genitalia, chromosomal make-up, hormonal treatment, or non-, pre-,
   or post-operative status; and (New HOD Policy)

2. That our American Medical Association supports that the facilities housing transgender
   prisoners shall not be a form of administrative segregation or solitary confinement. (New HOD
   Policy)

Fiscal note: Less than $500
REFERENCES

REPORT OF THE BOARD OF TRUSTEES

B of T Report 25-A-18

Subject: Recognition of Physician Orders for Life Sustaining Treatment (POLST) Forms (Resolution 20-A-17)

Presented by: Gerald E. Harmon, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws (Peter H. Rheinstein, MD, JD, MS, Chair)

At the 2017 Annual Meeting, the House of Delegates referred Resolution 20-A-17, “Recognition of Physician Orders for Life Sustaining Treatment (POLST) Forms,” introduced by the Organized Medical Staff Section, which asked:

That our American Medical Association advocate with appropriate government, legislative and regulatory bodies to recognize Physician Orders for Life Sustaining Treatment forms completed in one state as valid and enforceable in other states; and

That our AMA create a universal Physician Orders for Life Sustaining Treatment form that would be valid and enforceable in all states.

The reference committee heard testimony unanimously in support of the intent of the resolution. Testimony highlighted the challenges of respecting the medical care orders of patients when they cross jurisdictional boundaries. However, testimony also emphasized that a universal POLST form may be impractical because POLST is one of many end-of-life care frameworks in use in the United States.

The reference committee agreed that reciprocity of physician orders between states is important, but noted myriad problems with a universal POLST form. The Reference Committee suggested that “model state legislation be crafted in order for [reciprocity] to be accomplished in a way that can realistically be implemented” and referred the resolution. This Board Report provides background and discussion of interstate recognition of POLST and provides a recommendation.

BACKGROUND

Physician Orders for Life Sustaining Treatment were created in the 1990s in the state of Oregon in response to concerns that Do Not Resuscitate Orders (DNRO) had certain inadequacies; chief among them was their inability to transfer to other facilities (nursing homes, hospitals, hospice, ER’s, etc.) as the patient moved [1,2]. POLST was created to improve “end-of-life care by overcoming many of the advance directives’ limitations. It is designed to convert patient preferences for life-sustaining treatment into immediately actionable medical orders” that then “can be followed by medical personnel regardless of the patient’s location” [3,4]. POLST has largely been successful, with studies showing greater effectiveness in care “delivered in accordance with patient wishes” and recent years have seen increased adoption of the program in states around the country [5]. POLST is increasingly becoming established, alongside advance directives, as an important end-of-life decision making tool.
However, a problem has emerged with the recognition of POLST as patients cross state lines. There is a lack of uniformity in how states recognize a POLST from other states. This creates uncertainty if a POLST originating in one state will be followed in another state. This uncertainty risks the proper adherence of a patient’s desires regarding life-sustaining treatment as they travel from one state to another.

STATE LAW

To be effective, a POLST program must be universally recognized and honored. While POLST in each state aims to achieve the same goal of honoring patient wishes during a medical crisis, each state has its own requirements and procedures for a valid POLST.

POLST currently exists at some level in all 50 states and Washington, DC. Sixteen states explicitly recognize out-of-state POLST: Colorado, Delaware, the District of Columbia, Georgia, Idaho, Illinois, Iowa, Maryland, Nevada, New Jersey, New York, Oregon, Rhode Island, Utah, Vermont and West Virginia. Only one state expressly limits reciprocity. In Oklahoma, an out-of-state form is only valid for 10 days after patient’s admission into an Oklahoma medical facility [6]. In states with statutes that are silent on reciprocity, accepted medical practice or custom may allow recognition of an out-of-state POLST absent statutory guidance.

There are four main statutory approaches taken to POLST reciprocity: states may honor a POLST if it complies with the originating state’s requirements, if it complies with the receiving state’s requirements, if it reasonably satisfies the receiving state’s requirements or if it complies with either the originating or receiving state’s requirements. State laws vary on approach [7].

ETHICAL ISSUES

The scope of Resolution 20-A-17 is focused on the portability of POLST across state lines. In this context, significantly relevant is the ethical force of autonomy in end-of-life decision making and how it is central to continual support of POLST. “The POLST process increases the likelihood that each person will receive the desired care and not receive undesired care” [2]. Indeed, studies have also shown POLST to be successful in the “honoring of patient preferences” [8]. The fundamental ethical principle of patient autonomy (the driving force behind POLST) is the reason why, despite ethical shortcomings that exist with any end-of-life decision making model, POLST remains a durable clinical decision making tool. Therefore, there is ethical impetus to see greater portability of POLST across states lines, as the more likely a POLST from one state is enforced and recognized by another state, the greater likelihood that a patient’s autonomy at the end-of-life will be respected.

RELEVANT AMA POLICIES

End-of-life decision making is a significant issue in the medical profession and in the field of bioethics. As such, the AMA is strongly supportive of the concept and has published its support for such measures. For example, Chapter 5 of the Code of Medical Ethics focuses on caring for patients at the end of life. This chapter of the Code has several opinions supporting the concept of advance care planning and withholding life-sustaining treatment [9,10,11,12]. The Code explains that “advance care planning is widely recognized as a way to support patient self-determination” and that a patient “has the right to decline any medical intervention or ask that an intervention be stopped, even when that decision is expected to lead to his or her death” [9,11].
The AMA has additionally shown its support for end-of-life decision making through numerous House Policies and Directives [13,14,15,16,17,18]. Policies have called for the AMA to encourage people to establish advance directives and explain that advance directives “are the best insurance for individuals that their interests will be promoted in the event they become incompetent” [13,14]. Also, the AMA has adopted a directive to endorse “The Uniform Health-Care Decisions Act,” a uniform law designed to help govern, simplify, and standardize advance directives [18]. AMA policy does not address issues of reciprocity across jurisdictions.

DISCUSSION

Resolution 20-A-17 would instruct the AMA to create a universal POLST form. Drafting a universal POLST form is fraught with challenges as different jurisdictions have different hierarchies, rules and statutes with regards to end-of-life care. A universal form will not work across all states, as some states may not be able to adopt such a form.

The reference committee’s recommendation to create model legislation that would enable POLST reciprocity between the states is a more workable solution. This approach was recognized by the National POLST Paradigm Task Force (NPPTF) legislative group. The group, an assembly of health law experts tasked with providing perspectives to POLST legal issues, offered solutions, among other things, to the problem of POLST portability across state lines. The group recommended the adoption of a “uniform law” that would offer reciprocity of POLST across state lines. The NPPTF legislative group notes:

While it is still under revision and not directly applicable to POLST, one potential source of guidance is the draft Inter-jurisdictional Recognition of Substitute Decision-Making Documents Act from the National Conference of Commissioners on Uniform States Laws [19]. If adapted to POLST, the reciprocity provisions in this Act would deem a POLST form valid if, when completed, it complied with the law of the jurisdiction where it was completed [7].

However, a uniform law from the National Conference of Commissioners on Uniform State Laws specifically with regards to POLST is not yet in existence and remains a theoretical solution to the problem of POLST portability. Until such uniform law is available for consideration, states may elect to enact legislation establishing reciprocity to address current problems with POLST compliance across jurisdictions.

RECOMMENDATION

The Board of Trustees recommends that the following be adopted in lieu of Resolution 20-A-17, and that the remainder of this report be filed:

1. That our American Medical Association work with state medical associations to advocate with appropriate legislative and regulatory bodies to recognize Physician Orders for Life Sustaining Treatment forms completed in one state as valid and enforceable in other states; (Directive to Take Action) and

2. That our AMA draft model state legislation that will allow for reciprocity of POLST forms. (Directive to Take Action)

Fiscal Note: Modest—Between $1,000 and $5,000
REFERENCES


6. Okla. State 63 § 3105.3.


Resolution 11-A-17, “Revision of Researcher Certification and Institutional Review Board (IRB) Protocols,” sponsored by the Florida Delegation, was referred by the House of Delegates in June 2017. This resolution asks our AMA to:

   [S]tudy existing Collaborative Institutional Training Initiative standards, Institutional Review Board protocols and create recommendations that would simultaneously protect patients and permit physicians to easily participate in the dissemination of medical knowledge.

HUMAN SUBJECTS PROTECTIONS

Concerns about the ethical conduct of research involving human participants date back to the 19th century, well before the evolution of the current regulatory framework in the U.S. [1]. The principles underlying the current system of oversight of human subjects protections were set out in the 1979 Belmont Report by the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research [2], and subsequently codified in regulations adopted by the Department of Health and Human Services (DHHS) and by 14 departments and agencies a decade later—the “Common Rule” [3]. The Common Rule sets basic standards for research oversight, including the establishment of institutional review boards (IRBs) and review procedures, and criteria for individual informed consent [4]. The goal of this—and similar regulatory efforts in other countries—is to protect the rights and well-being of individuals who participate as subjects in biomedical and behavioral research.

The Common Rule has been criticized as ineffective, cumbersome, and of questionable value in actually protecting research participants [5-7]. A 2011 review of empirical studies indicated, for example, that there is considerable variation in IRB structure, membership, processes, and in outcomes of IRB reviews [6]. A recent study of whether and how essential elements of human subjects protection are implemented during institutional review or research protocols found considerable variation among 20 participating IRBs [8]. The current system of oversight has also been critiqued as unable to address effectively the challenges of today’s research landscape, especially in light of the increasing prominence of multi-site research involving large numbers of participants and research involving large data sets or collections of biospecimens, and their implications for informed consent [9].

In 2011, the DHHS launched a review and reassessment of the Common Rule, issuing an Advanced Notice of Proposed Rule Making (ANPRM) seeking public comment to enhance protection of research subjects and improve the process of research review [10].
Four years later, DHHS issued a Notice of Proposed Rule Making (NPRM) soliciting comment on proposed updated policy. Stakeholders opposed the NPRM’s proposal to require consent for secondary research use of unidentified biospecimens, but supported proposals for improving informed consent, especially for simplifying consent forms while suggesting some modifications, which are reflected in the Final Rule issued in January 2017 [11-12]. The Final Rule also retains provisions intended to reduce unnecessary regulation and streamline oversight processes, including creating new categories of exemption from IRB review for low-risk studies, eliminating the requirement of continuing review for some categories of research, and introducing new options for facilitating screening of prospective participants. (On January 19, 2018, DHHS issued notice that it would delay the compliance deadline for the updated Common Rule to July 19, 2018 [13].)

In 2008 and 2009, AMA shared its concern that over interpretation of Common Rule protections in the context of quality improvement activities imposed unnecessary regulatory burdens on important research [14-16]. AMA also provided input under the auspices of the Advanced Notice of Proposed Rule Making [17] and the Notice of Proposed Rule Making [18].

EDUCATING THE RESEARCH COMMUNITY ABOUT HUMAN SUBJECTS PROTECTIONS

The National Institutes of Health requires that “key personnel” on NIH-funded research involving human subjects receive education on protecting human subjects [19]. These include principal investigators and all other individuals who are responsible for the design or conduct of the research, including foreign awardees or foreign subcontractors and third party personnel or consultants, even if they are not compensated through the NIH award, as well as investigators involved in research that is exempt from IRB review. Investigators in research with human specimens, tissues, or data that has been determined not to involve human subjects in keeping with guidance from the Office for Human Research Protections (OHRP) are not required to fulfill the educational requirement, nor are personnel who are not involved in the design and conduct of human subject research. NIH leaves the decision of what educational programs to use to meet this requirement to investigators’ home institutions. The NIH Clinical Center offers free online education that institutions may elect to meet the education requirement.

In addition, the Collaborative Institutional Training Initiative (CITI) offers web-based education in human subjects protections developed by experts in research ethics, ethics committee process, and web-enabled learning [20-21]. Initially created in 2000 in response to the then newly announced NIH education requirement for agency grantees, CITI’s offerings have expanded over time to encompass a robust catalogue of instruction in multiple aspects of the responsible conduct of research. Modules are available to learners through institutional subscriptions (at a current cost of $3,400/year) or for purchase by individuals (“independent learners”) (currently $130/module).

Training is also available specifically for IRB members. OHRP, for example, offers periodic workshops on various topics in human subjects protections and has developed extensive policy guidance. It also offers practical tools to clarify interpretation of the Common Rule and help IRBs evaluate research protocols effectively; for example, decision charts to help IRBs answer such key questions as whether a proposed study involves human subjects, whether it is exempt from IRB review (or eligible for expedited review), or whether informed consent may be waived. Educational resources for IRBs are also available through organizations such as Public Responsibility in Medicine and Research (PRiMR), which offers certification for IRB professionals [5].

Although there are reservations about their effectiveness in meaningfully protecting human subjects, efforts have also been launched to accredit IRBs. Thus the Association for the
Accreditation of Human Research Protection Programs (AAHRPP) promotes quality standards and performance improvement for IRBs and institutional human research protection programs [6].

INSTITUTIONAL AND JOURNAL POLICIES

Institutions that carry out federally funded research, as well as professional journals that publish the findings of research with human subjects have similarly established expectations that research personnel will adhere to human subjects protections in keeping with federal regulations. For example, the University of Illinois at Champaign Urbana requires that researchers complete CITI’s “Core Basic Training for either social/behavioral research or biomedical research,” and more specialized modules as may be needed for the purposes of specific studies, such as those involving children [22]. The University of California-Berkeley likewise requires that faculty, students, and staff engaged in human subjects research complete appropriate CITI [23], while San Francisco State University requires “all researchers using research volunteers to pass an online research training course,” and provides links to both NIH and CITI courses [24]. Other institutions—e.g., Vanderbilt University School of Medicine [25], Duke University School of Medicine [26] — require completion of in-person courses or other educational programs developed by the institution to address NIH educational requirements for research carried out with human subjects.

Professional journals frequently require that authors reporting findings of social/behavioral or biomedical research with human subjects attest that the study presented adhered to human subjects protections and appropriate oversight. The International Committee of Medical Journal Editors (ICMJE) recommends that investigators ensure that “the planning, conduct, and reporting of human research” is in accord with the Declaration of Helsinki, the international statement of research ethics promulgated by the World Medical Association [27]. The Journal of the American Medical Association and JAMA Network journals, for example, require that authors of manuscripts reporting studies that involve human participants or animals submit documentation demonstrating formal review and approval (or waiver) of the research and describe the review and its determination [28]. Annals of Internal Medicine likewise requires authors to confirm appropriate review or affirm that the research reported is consistent with the principles of the Declaration of Helsinki [29], while The Lancet advises prospective contributors that it adheres to the ICMJE Recommendations [30].

AMA POLICY


CONCLUSION

Oversight of research that involves human participants must balance important interests of science, the community, and individuals. Commitment to protecting the well-being and rights of individuals who agree to participate in research is fundamental to the ethics of the medical profession and to public trust.
Significant attention has been given in recent years to enhancing the system of research oversight in ways that sustain robust protections for human participants while streamlining processes of review and oversight and minimizing the burden on investigators. As scholars recently noted in relation to the Common Rule, “In an age of big data and cybersecurity threats, and as new technologies reveal personal identities, ethics rules become even more important. Federal oversight will remain the bulwark against unethical practices. In the end, treating human research participants with respect and fairly is essential for continuing public support of vital scientific investigations” [31].

RECOMMENDATION

In light of the importance of protecting the well-being and rights of research participants and the considerations reviewed above, your Board of Trustees recommends that the following be adopted in lieu of Resolution 11-A-17, “Revision of Researcher Certification and Institutional Review Board (IRB) Protocols,” and the remainder of the report be filed:

That our AMA continue to support efforts to improve protections for human subjects of biomedical and behavioral research and advocate for change as opportunities arise. (New HOD Policy)

Fiscal Note: Less than $250
REFERENCES

14. Edward L. Langston, MD, Chair to Samuel Tilden, MD, JD, LLM, Chair, Secretary’s Advisory Committee on Human Research Protections. January 18, 2008.
17. James L. Madara, MD, EVP to Jerry Menikoff, MD, JD, Director, Office for Human Research Protections, October 26, 2011.
18. James L. Madara, MD, EVP to Jerry Menikoff, MD, JD, Director, Office for Human Research Protections, January 5, 2016.


28. The JAMA Network. *Instructions for Authors*. Available at [https://jamanetwork.com/journals/jama/pages/instructions-for-authors#SecAuthorshipandDisclosures](https://jamanetwork.com/journals/jama/pages/instructions-for-authors#SecAuthorshipandDisclosures). Accessed January 24, 2018.


Subject:  CCB Sunset Review of 2008 House Policies

Presented by:  Colette Willins, MD, Chair

Referred to:  Reference Committee on Amendments to Constitution and Bylaws
(Peter H. Rheinstein, MD, Chair)

At its 1984 Interim Meeting, the House of Delegates (HOD) established a sunset mechanism for House policies (Policy G-600.110, “Sunset Mechanism for AMA Policy”). 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 House of Delegates deliberations.

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

• As the House of Delegates adopts policies, a maximum ten-year time horizon shall exist. A policy will typically sunset after ten years unless action is taken by the House of Delegates to retain it. Any action of our AMA House that reaffirms or amends an existing policy position shall reset the sunset “clock,” making the reaffirmed or amended policy viable for another 10 years.

• In the implementation and ongoing operation of our AMA policy sunset mechanism, the following procedures shall be followed: (a) Each year, the Speakers shall provide a list of policies that are subject to review under the policy sunset mechanism; (b) Such policies shall be assigned to the appropriate AMA councils for review; (c) Each AMA council that has been asked to review policies shall develop and submit a report to the House of Delegates identifying policies that are scheduled to sunset. (d) For each policy under review, the reviewing council can recommend one of the following actions: (i) Retain the policy; (ii) Sunset the policy; (iii) Retain part of the policy; or (iv) Reconcile the policy with more recent and like policy; (e) For each recommendation that it makes to retain a policy in any fashion, the reviewing council shall provide a succinct, but cogent justification. (f) The Speakers shall determine the best way for the House of Delegates to handle the sunset reports.

• Nothing in this policy shall prohibit a report to the HOD or resolution to sunset a policy earlier than its 10-year horizon if it is no longer relevant, has been superseded by a more current policy, or has been accomplished.

• The AMA Councils and the House of Delegates should conform to the following guidelines for sunset: (a) when a policy is no longer relevant or necessary; (b) when a policy or directive has been accomplished; or (c) when the policy or directive is part of an established AMA practice.
that is transparent to the House and codified elsewhere such as the AMA Bylaws or the AMA
• The most recent policy shall be deemed to supersede contradictory past AMA policies.
• Sunset policies will be retained in the AMA historical archives.

In this report, the Council on Constitution and Bylaws presents its recommendations on the
disposition of the House policies from 2008 that were assigned to it. The Council’s
recommendations on policies are presented in the Appendix to this report.

RECOMMENDATION

The Council on Constitution and Bylaws 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.

Fiscal Note: Less than $500 to update policy database.
## APPENDIX – Recommended Actions on 2008 House Policies

<table>
<thead>
<tr>
<th>Policy Number/Title</th>
<th>Text</th>
<th>Recommended Action and Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>H-10.972, Blocked Fire Exits</td>
<td>AMA policy is that fire exits remain unlocked at all meetings of Federation members. The AMA will issue a statement that physicians should make certain that the observable fire exits are unlocked at any public gathering which they attend.</td>
<td>Sunset. Over the past 20 years fire safety regulations have been comprehensively promulgated by the International Code Council International Fire Code and the National Fire Protection Association Fire Protection Code, elements of which are included in all state and municipal fire codes. Codes distinguish between a fire exit and a fire door. A fire exit is an external door, which also functions as a security door. If locked to prevent unauthorized access from the outside, it must be fitted with a panic or push bar. Fire exit doors may also be fitted with a key lock override to allow outside access. A fire door is required to be kept closed at all times unless certified retainers are installed to hold it door open until a fire alarm is set off.</td>
</tr>
<tr>
<td>H-25.996, Retirement and Hiring Practices</td>
<td>It is urged that physicians, individually and through their constituent, component, and specialty medical societies, continue to stress the need to reappraise policies calling for compulsory retirement and age discrimination in hiring from the standpoint of health among older people, and that they participate actively and lend medical weight in the efforts of other groups to create a new climate of opportunity for the older worker.</td>
<td>Retain as editorially amended.</td>
</tr>
<tr>
<td>H-405.991, Volunteerism and Community Service</td>
<td>The AMA supports continued promotion of community service and volunteerism by its membership.</td>
<td>Reconcile with H-405.996, Voluntary Service by Physicians, “Our AMA does not believe it would be appropriate to establish a separate committee to serve as a clearinghouse for service opportunities and to promote voluntary service, but encourages state association awards for exceptional voluntary community service and wider recognition of physicians who perform voluntary services.”</td>
</tr>
<tr>
<td>H-445.999, Chambers of Commerce</td>
<td>The AMA reaffirms its previously adopted recommendation to all state medical societies that they become active in the U.S. and state chambers of commerce and requests that a similar recommendation be made to all county medical societies so that they too might be encouraged to become active in local, state and U.S. chambers of commerce programs.</td>
<td>Sunset. Action requested has been accomplished.</td>
</tr>
</tbody>
</table>
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.
Subject: Competence, Self-Assessment and Self-Awareness

Presented by: Dennis S. Agliano, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws (Peter H. Rheinstein, MD, JD, MS, Chair)

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

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 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 demeans the patient, undermines the patient’s relationship with the physician and the health care system, and can result in significant health disparities across entire communities [31]. This is of particular concern for patients who are members of minority and historically disadvantaged populations [31]. Physicians may fall victim to the tendency to seek out information that confirms established expectations or dismiss contradicting information that does not fit into predetermined beliefs (confirmatory bias) [28]. These often inadvertent thought processes can result in a physician pursuing an incorrect line of questioning or testing that then leads to a misdiagnosis or the wrong treatment.
No matter how well a patient may seem to fit a stereotype, it is imperative that the physician look beyond categories and assumptions to investigate openly the health issues experienced by the patient. Although all human beings exhibit both conscious and unconscious habits of perception, physicians must remain vigilant in not allowing preconceived or unexamined assumptions to influence their medical practice.

**Overconfidence**

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

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

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

**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; and

(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.

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


Mergers between secular and religiously affiliated hospitals are changing the landscape of health care across the United States. This report by the Council on Ethical and Judicial Affairs (CEJA) offers ethics guidance to address the challenges such mergers can pose for patients, physicians, health care institutions and the communities they serve.

**RELIGIOUSLY AFFILIATED HEALTH CARE INSTITUTIONS**

The concept of the hospital as a facility providing inpatient care for the sick originated with the Catholic Church, with the original and enduring dual mission of healing the body and promoting spiritual well-being [1]. The mission of today’s Catholic Health Association remains focused on the needs of those who are “poor, underserved, and most vulnerable” [2]. Although hospitals established by Protestant denominations and Jewish-identified facilities remain important segments of U.S. health care, Catholic facilities predominate among religiously affiliated institutions—U.S. Catholic Health Care is the largest nonprofit care provider in the country [2].

Since the 1990s, mergers between secular and religiously affiliated hospitals and health care institutions have been reshaping the landscape of health care in the United States, for both patients and physicians. Driven by economic considerations and changes in health policy, notably in recent years emphasis on accountable care organizations and bundled payments [1,3], mergers have enabled facilities in some cases simply to survive and in others to thrive within their communities. Consolidation has enabled hospitals to control a greater share of their local markets and to negotiate effectively with insurers [4].

Religiously affiliated hospitals and facilities benefit from the tax-exempt status of the religious institutions they represent and from other tax subsidies that derive from their mission to serve the poor and provide charitable care [5]. Although the majority of religiously affiliated hospitals remain nonprofit, the number of for-profit hospitals affiliated with religious institutions increased by 22 percent between 2001 and 2016 [6]. Religiously affiliated health care facilities—which encompass clinics, hospitals, and long-term care facilities—are also important employers. According to the Catholic Health Association, as of 2017 member facilities employed more than 500,000 full-time and 200,000 part time staff [2].

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* 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 some communities, religiously affiliated health care institutions may be the only providers—
as of 2015, 132 of the nation’s approximately 1,300 critical access hospitals were members of U.S.
Catholic Health Care [2]. In some areas, more than 40 percent of short-term, acute care beds are in
Catholic facilities [6]. Nationwide, one in every six patients now receives care in a Catholic
hospital [2].

THE DILEMMA OF MERGERS

The consolidation of a religiously affiliated institution with a secular health care facility raises
challenges for all stakeholders—the facilities, their communities, their patients, and the physicians
and other professionals who provide care. All religiously affiliated institutions seek to remain
faithful to their defining mission and values, which can place them in tension with their secular
counterparts. Catholic facilities, however, are embroiled in an increasingly public debate about the
implications and effects of entering into arrangements with secular institutions as they seek to
retain their identity and mission and still survive in the health care market place. Thus they offer a
window through which to understand the ethical dimension of health care mergers.

As the Ethical and Religious Directives that govern care in Catholic health care facilities observe:

New partnerships can be opportunities to realign the local delivery system in order to provide a
continuum of health care to the community; they can witness to a responsible stewardship of
limited health care resources; and they can be opportunities to provide to poor and vulnerable
persons a more equitable access to basic care.

On the other hand, new partnerships can pose serious challenges to the viability of the identity
of Catholic health care institutions and services, and their ability to implement these Directives
in a consistent way, especially when partnerships are formed with those who do not share
Catholic moral principles (§VI)[7].

From this perspective, in the contemporary health care market place Catholic hospitals “are caught
in an impossible bind” [1]. Like other hospitals, financial pressures drive them to consolidate with
other institutions to become more economically efficient. Yet “competing in the aggressive world
of the medical business industry” can put Catholic hospitals’ historical commitment to the poor at
risk [1]. At the same time, gaining financial security may risk “imperceptibly compromising their
traditional Catholic witness” when compromises are made with respect to Directives [1].

From the perspective of those they serve, a merger or consolidation may help guarantee the
continued presence of health care in a community, but may also limit the range of services
available to patients when the consolidated entity adheres to the Directives. Certain treatment
choices for care at the end of life, reproductive health care services, and, by some reports, certain
services for transgender individuals may all be affected [4,8,9]. Limitations on women’s health
services have been a focus of concern for obstetricians and gynecologists associated with or
employed by religiously affiliated hospitals [10], with reports of conflict over both elective and
clinically indicated surgical sterilization [11,12], and management of miscarriage [13]. Restricted
access to services can have a disproportionate impact on poor women, and women in rural areas
where religiously affiliated institutions are the only providers of care [14].

From the perspective of physicians and other health care professionals affiliated with or employed
by the entity that results from a merger can challenge professional commitments. A merger that
results in loss of access to services for the community and requires physicians to follow the
religious guidelines embodied in the Directives may result in “conflict with prevailing medical
standards of care and ethical principles of health care professional” [15]. Physicians and other
health care professionals who are not members of the faith tradition may find themselves
contractually prohibited from providing care that is otherwise legal and, in their professional
judgment, clinically appropriate and ethically permissible under the norms of medical
professionalism.

THE RESPONSIBILITIES OF LEADERSHIP

As challenging as mergers between secular and religiously affiliated health care facilities may be
for individual patients and physicians, addressing dilemmas of mission is pre-eminently a
responsibility of hospital leadership.

For Catholic facilities merging with secular facilities (or facilities associated with other religious
traditions), a touchstone is the principle of cooperation [16,17]. The principle, it is argued, is a
necessity for business relationships in a pluralistic world, providing a way to address the reality
that, for the faithful, “it is almost impossible to bring about good without brushing up against or
even becoming somewhat involved in the wrongdoing of others” [16]. The principle of cooperation
is understood “as a limiting principle, to avoid cooperating in evil” (original emphasis) [17].

The essential goal is to ensure that institutional arrangements allow the facility and its staff to
“remain as removed as possible” from violations of the Directives and “not [to] contribute anything
essential to make possible the wrongdoing’s occurring” [16]—e.g., essential employed staff or
equipment for the performance of what under the Directives is an immoral procedure [17]. Whether
services that would be otherwise prohibited by the Directives will or may be available through the
merged entity is importantly a function of how caregiving is organized in the resulting composite
system. The approval of the diocesan bishop is required for mergers involving facilities subject to
his governing authority, and the diocesan bishop has final authority for assessing whether a
proposed merger constitutes morally licit cooperation (§VI) [7].

Analogous discussions of the ethics of trusteeship, such as that offered by The Hastings Center,
offer secular insight for thinking about the responsibilities of leaders in health care institutions.
Trustees of not-for-profit health care organizations “regularly make decisions that affect the lives
and well-being of a large number of people who are relatively powerless, relatively vulnerable, and
in need of services or assistance” [18]. In light of the mission of such organizations, service on a
board of trustees entails fiduciary duties to founders, benefactors, and donors and responsibility to
ensure that the organization realizes the public benefits for which it enjoys tax exempt status.

Trustees are held to principles of fidelity to mission; service to patients, ensuring that the care is
high quality and provided “in an effective and ethically appropriate manner”; service to the
community the hospital serves, deploying hospital resources “in ways that enhance the health and
quality of life” of the community; and institutional stewardship. They have a further responsibility
to ensure that when there is conflict over fundamental values and principles, “all points of view are
heard and taken seriously, that reasonable compromise is explored, and that consensus has time to
form” [18].

The Principles of Integrated Leadership for Hospitals and Health Care Systems, developed in
collaboration by the American Hospital Association (AHA) and the American Medical Association
(AMA), address responsibilities of hospital leadership in the context of rapidly evolving models of
integrated physician-hospital health care systems [19]. In addition to governance and management
structure and leadership development, guidance identifies “cultural adaptation” as a key element
for success, observing that:
Culture is the way an organization, institution or integrated health system does business, in a way that is predictable, known to all and consonant with the mission and values of the organization, institution or integrated health system. The creation of a common shared culture that includes an integrated set of values is important to serve as a guide to the entity and will serve as a touch point to help resolve the inevitable conflicts that will arise [19].

The AHA-AMA’s principles for *Integrated Leadership for Hospitals and Health Systems* urge integrated health systems to cultivate the characteristics of adaptive institutional culture, including a focus on the health of the entire population served; agreement to a common mission, vision, and values; mutual understanding and respect; and a sense of common ownership of the entity and its reputation [19].

**INSIGHT FROM THE CODE OF MEDICAL ETHICS**

As frontline clinicians, physicians (and other health care professionals) regularly confront the effects on patients’ lives and well-being of the institutional arrangements through which care is delivered. They have a responsibility to advocate for the resources patients need, as well as to be responsible stewards of the resources with which they are entrusted [20]. They must be able to make treatment recommendations in keeping with their best judgment as medical professionals [21]. And they are expected to uphold the ethical norms of medicine, including fidelity to patients and respect for patients as moral agents and decision makers [22].

Existing guidance on exercise of conscience by individual physicians suggests essential responsibilities of leadership in health care as well [22]. These include responsibility to engage in thoughtful consideration of the implications of institutional arrangements—whether arrangements sustain or risk undermining the personal and professional integrity of staff, cause moral distress, or compromise the ability to provide care. Leaders in health care institutions must be mindful that arrangements do not discriminate against or unduly burden individual patients or populations of patients, and of the burden arrangements may place on fellow professionals. And they must accept responsibility to take steps to ensure that services will be available to meet the patients and community the institution serves.

**RECOMMENDATION**

In light of this analysis, the Council on Ethical and Judicial Affairs recommends that the following be adopted, and the remainder of this report be filed:

The merger of secular health care institutions and those affiliated with a faith tradition can benefit patients and communities by sustaining the ability to provide a continuum of care locally in the face of financial and other pressures. Yet consolidation among health care institutions with diverging value commitments and missions may also result in limiting what services are available. Consolidation can be a source of tension for the physicians and other health care professionals who are employed by or affiliated with the consolidated health care entity.

Protecting the community that the institution serves as well as the integrity of the institution, the physicians and other professionals who practice in association with it, is an essential, but challenging responsibility.

Physician-leaders within institutions that have or are contemplating a merger of secular and faith-based institutions should:
(a) Seek input from stakeholders to inform decisions to help ensure that after a consolidation the same breadth of services and care previously offered will continue to be available to the community.

(b) Be transparent about the values and mission that will guide the consolidated entity and proactively communicate to stakeholders, including prospective patients, physicians, staff, and civic leaders, how this will affect patient care and access to services.

(c) Negotiate contractual issues of governance, management, financing, and personnel that will respect the diversity of values within the community and at minimum that the same breadth of services and care remain available to the community.

(d) Recognize that physicians’ primary obligation is to their patients. Physician-leaders in consolidated health systems should provide avenues for meaningful appeal and advocacy to enable associated physicians to respond to the unique needs of individual patients.

(e) Establish mechanisms to monitor the effect of new institutional arrangements on patient care and well-being and the opportunity of participating clinicians to uphold professional norms, both to identify and address adverse consequences and to identify and disseminate positive outcomes.

Individual physicians associated with secular and faith-based institutions that have or propose to consolidate should:

(f) Work to hold leaders accountable to meeting conditions for professionalism within the institution.

(g) Advocate for solutions when there is ongoing disagreement about services or arrangements for care.

(New HOD/CEJA Policy)

Fiscal note: Less than $500
REFERENCES


Every year, a growing number of “medical tourists” cross borders to receive treatments and procedures, including elective cosmetic services that are less costly than in their home countries; “medically necessary” care that is available at lower cost or in a more timely fashion; for access to nonvalidated therapies or other services that for ethical or legal reasons are not available in the health care system where the patient resides. Sometimes patients travel at the recommendation of their own physicians or under the auspices of programs initiated by their health plans or employers; sometimes patients travel on their own initiative, with or without consulting their physician, and with or without utilizing the services of commercial medical tourism companies.

Many aspects of medical tourism confound core ethical expectations regarding patients’ rights—to informed consent, continuity of care and access to their medical records (E-1.1.3)—and physicians’ responsibilities—to promote quality of care (E-1.1.6) and patient safety (E-8.6), to be prudent stewards of health care resources.

Physicians need to be aware of the implications of medical tourism for individual patients and the community. Collectively, the profession should support access to outcomes data about medical tourism and advocate for appropriate education for health care professionals as well as for appropriate oversight of medical tourism.

Individually, physicians should familiarize themselves with issues in medical tourism, including risks and possible benefits, to help support informed decision making when patients approach them about seeking care abroad and offer professional guidance as they would for any decision about care. They should advise patients who consult them in advance whether they are or are not willing to provide follow up care. Physicians should respond compassionately when patients who did not discuss traveling for care return seeking nonemergent follow-up services. Before declining to provide such care, physicians should consider carefully the nature and duration of their relationship with the patient, the likely impact on the patient’s well-being, the burden declining to provide care may impose on fellow professionals, and the likely impact on the health and resources of the community.
Subject: Medical Tourism

Presented by: Dennis S. Agliano, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Peter H. Rheinstein, MD, JD, MS, Chair)

Policy H-460.896(a), “Stem Cell Tourism,” adopted at the 2016 Annual meeting, calls on the American Medical Association (AMA) to encourage study of “appropriate guidance for physicians to use when advising patients who seek to engage in stem cell tourism and how to guide them in risk assessment.”

In keeping with this policy, the Council on Ethical and Judicial Affairs (CEJA) was asked to develop ethics guidance for physicians in this area. Based on its review of relevant literature and its deliberations, the council concluded that guidance focusing on the broader phenomenon of medical tourism, of which stem cell tourism is only one example, would better serve the profession. The following report and recommendations thus provide broad guidance for physicians who interact with patients who seek or have received medical care outside the U.S.

EMERGENCE OF MEDICAL TOURISM

Every year, a growing number of “medical tourists” cross borders to receive treatments and procedures, often treatments that are unaffordable or unavailable to them at home [1]. In its broadest sense, “medical tourism” refers to any occasion on which patients travel outside their home geographic area to receive medical care elsewhere—for example, traveling to a center of excellence in another city or state. As most commonly used today, however, medical tourism refers to traveling to a foreign country to receive care. It encompasses international travel by wealthy patients from lower wage countries to medical centers in higher wage countries, notably the U.S. [2]. Increasingly, however, medical tourism is understood as travel in the opposite direction, from higher wage countries to less affluent countries where medical services are available at lower cost [2,3].

Estimations of how many patients travel abroad for care vary considerably, but appear to exceed one million [4,5]. In some instances, patients travel abroad for care at the recommendation of their own physicians or under the auspices of programs initiated by their health plans or employers [2,6,7]. In others, patients travel on their own initiative, with or without consulting their physician, and with or without utilizing the services of commercial medical tourism companies [2].
Medical tourists travel to address what they deem to be unmet personal medical needs [8], prompted by issues of cost, timely access to services, higher quality of care or perceived superior services, or to access services that are not available in their country of residence [9,10]. Patients may also go outside their usual health care system to achieve other goals, for example, to preserve anonymity [11]; immigrant patients may return to their country of origin to receive care in culturally familiar settings [9]. The care medical tourists seek may be elective procedures; medically necessary standard care; or care that is unapproved or legally or ethically prohibited in their home system [12].

Elective Procedures: “Cosmetic Tourism”

A significant and expanding portion of the medical tourism industry is comprised of individuals who seek cosmetic procedures that are available in their home country but are offered at often considerably lower cost elsewhere [11,13,14]. For example, 2011 data indicate that breast implants that would have cost approximately $6,000 in the U.S. were available for about 43 percent of that cost in Thailand (approximately $2,600) and less than 25 percent (approximately $1,248) in Cuba [11]. Because cosmetic procedures are generally not covered by insurance plans and patients must pay out of pocket, going abroad for a desired procedure can be an attractive option. However, as Australian researchers noted, “[t]he model of care by which these services are delivered limits preoperative assessment and follow up to a few days to a week” [14].

Medically Necessary Care: “Transplant Tourism”

Medical tourism also encompasses care that would be deemed “medically necessary,” such as cardiac care (coronary artery bypass grafts, heart valve replacements, angioplasty) and orthopedic surgery (hip and knee replacement, hip resurfacing, spinal fusion) [15]. Patients from publicly funded health care systems, such as Canada, Australia, or the U.K., cite long wait times at home as a primary reason for seeking care abroad [16], although they could receive needed care in their home system. Uninsured or underinsured patients in predominantly private health care systems, such as the U.S., travel to access needed care that would otherwise not be available to them [3].

Over the past decade “transplant tourism” has emerged as a particularly problematic form of medical tourism. As one critique noted, many of the patients who go abroad for an organ transplant are “middle-income Americans evading impoverishment by expensive, medically necessary operations” [17]. Self-insured employers may encourage transplant tourism in an effort to contain health care costs [18]. A study of transplant tourists who presented for follow-up care at one U.S. facility found that these patients “had a substantially lower mean dialysis time before transplantation” compared with patients who underwent transplant at the institution [19]. By one estimate, as of 2007 some 10 percent of transplants worldwide involved commercial sales of organs [20]. Organ trafficking and the exploitation of vulnerable donors in resource poor countries associated with transplant tourism led the international transplant community in 2008 to adopt principles intended to curb unethical transplant practices [20].

Unapproved/Investigational Therapies: “Stem Cell Tourism”

Other than therapies for blood disorders, there is no evidence that stem-cell-based interventions are efficacious. Yet the market in stem cell tourism continues to grow—by 2012 some 700 clinics worldwide offered stem cell therapy for spinal cord injury, cardiovascular disease, Parkinson’s and
a host of other conditions [21]. For the most part, these therapies are unapproved and unregulated [21,22].

A recent case highlights the dangers of stem cell therapy. Richard Gass, a retired attorney in the U.S., suffered a stroke that left one arm paralyzed and one leg with weakness. Although he was able to live independently, he encountered a story about the miraculous physical recovery of a professional athlete who had traveled to Russia for stem cell treatments following a serious injury. Convinced of the promise stem cell treatments could bring, and undeterred by his family’s concerns about the dangers of these therapies, he traveled to Mexico to receive stem-cell injections. Despite improvement in his mobility early on, within months Gass became paralyzed from the neck down. When he sought follow-up care from his U.S. health care team, they discovered that a large, rapidly growing tumor along his spine derived from foreign cells that could not be completely removed [23].

In 2013, the International Society for Stem Cell Research called on governments and professional organizations to discourage commercial provision of (autologous) stem cell interventions outside of clinical trials [24]. Governments are moving to strengthen or more stringently enforce legal regulations where they exist [25]. For example, the U.S. Food and Drug Administration has issued draft guides that increase clarity and suggest that the U.S. Food and Drug Administration is preparing to take increased regulatory action in response to stem cell interventions offered domestically [26].

Proscribed Therapies: “Reproductive Tourism” (“Fertility Exile”)

As another area of medical tourism, travel for reproductive services highlights in particular issues involving access to services that for legal or ethical reasons are not available in the health care system where the patient(s) reside, or that are denied to certain categories of patients [27,28]. Hence the suggestion that such travel might better be described as “fertility exile” [29]. As reproductive tourists, patients may cross borders to receive services that are not legally available in their home health care system (e.g., pre-implantation genetic diagnosis); services for which they do not qualify in their home system by reason of age or marital status (e.g., in vitro fertilization); or services denied by their home health care institutions or health systems based on social rather than clinical considerations (e.g., gestational surrogacy for male same-sex couples) [28]. By one estimate, some 5,000 cross-border IVF treatment cycles were performed in 25 countries in 2008 [30].

Like transplant tourism, reproductive tourism raises concerns about the exploitation of vulnerable populations and the commercialization of human biological materials, as well as about discrimination against classes of patients [28,30,31]. Travel for unapproved or prohibited services can also exploit medical tourists themselves, of course, when it trades on false hope [12].

IMPLICATIONS FOR PATIENTS, PHYSICIANS & HEALTH CARE SYSTEMS

Many medical tourists receive excellent care, but data suggest that issues of safety and quality can loom large. Substandard surgical care, poor infection control, inadequately screening of blood products, and falsified or outdated medications in lower income settings of care can pose greater risks than patients would face at home [32,33]. Patients who develop complications may need extensive follow-up care when they return home; for those who return with infections, the differential diagnosis is often broader than in their home country, further complicating follow-up care [33]. The often short recovery periods following treatment abroad also mean medical tourists
can face greater risk for deep vein thrombosis, pulmonary embolism, or other travel-related complications [5,14,33].

For example, in 2013, the Maryland Department of Health and Mental Hygiene dealt with the repercussions of medical tourists traveling outside the U.S. for cosmetic surgery. Public health officials, working with the CDC, identified 21 patients from six states who had traveled to the Dominican Republic for cosmetic procedures (liposuction, abdominoplasty, buttocks augmentation, breast augmentation, and breast reduction); 18 were confirmed to have rapidly growing *Mycobacterium abscessus* (RGM), likely because of poor sterilization procedures during their surgeries [13]. All patients were successfully treated, but their course of care was complicated.

Among the nine patients for whom chart data were available, median onset of illness was 24 days after their surgical procedure. Of the five from whom RGM culture was positive, median time to laboratory confirmation was 79 days after their first presentation for care in the U.S. Eight were hospitalized in the U.S., five of them on more than two occasions. All nine underwent at least one therapeutic surgical procedure; seven required courses of antibiotics for three months or longer; seven were prescribed more than five different classes of antibiotics [13].

Cost of post-surgical care can also be a concern. Of the patients who responded to requests for information about cost, 13 used medical insurance, although four indicated that their insurer had declined to cover some costs. Ten patients indicated the illness had caused financial problems; two reported that indirect costs, such as inability to work, compounded their financial difficulty [13]. A review of data for patients hospitalized at London’s Royal Free Hospital between 2015 and 2017 following plastic surgery outside the U.K. found that among 21 patients, complications led to 18 in-patient admissions and 46 surgical procedures overall. The total cost of follow up care was £282,000 (U.S. $368,600); cost per patient averaged £13,500 (slightly less than U.S. $18,000) [34].

Chart review at Gold Coast University Hospital in Queensland, Australia, similarly found that between 2012 and 2013, the facility treated 12 patients for complications following cosmetic surgery abroad—including not only infection, but also pulmonary embolism—at a cost of AUS151,172.52 (approximately $115,800 U.S.) [14]. Similar additional costs are reported by U.S. facilities [5].

Medical tourism carries implications for patients’ home communities as well. For example, the financial costs of needed follow-up care fall on health care institutions and health insurers [10,12,32], which may be especially problematic in publicly funded health care systems [10,14]. Medical travel poses public health risks, providing means for moving bacteria and resistant genes globally [33]. The fact that patients may return to multiple home institutions from a single destination treatment center underscores the need for tracking medical travel and outcomes that currently is not being met [14,33].

Additionally, medical tourism carries implications for destination communities and health care systems. It can foster dual systems of care, one catering to medical tourists, and one for the local population, a situation that risks exacerbating health inequity [10,32,35]. Development of commercial health care institutions to serve medical tourists risks creating, in the words of one author, “islands of medical excellence in a sea of medical neglect” [31]. Transplant and reproductive tourism in particular pose significant risk that vulnerable local populations will be exploited as donors of biological materials that benefit foreign patients [20,31].

GUIDANCE FROM PROFESSIONAL ORGANIZATIONS

In 2008, the American Medical Association adopted H-450.937, “Medical Care outside the United States,” which advocates that entities that “facilitate or incentivize” medical care outside the U.S.
ensure that such care is voluntary, take care that financial incentives neither limit the alternatives offered to patients nor restrict treatment or referral, and refer patients only to internationally accredited institutions. Policy further urges that local follow-up care and financing be coordinated prior to travel and that coverage include costs of necessary follow-up care in the U.S. Patients should be informed about their rights and legal recourse and should have access to information about the foreign facility and health care professionals, the potential risks of combining surgical procedures with travel, and outcomes data for the procedure(s) they will undergo. Transfer of medical records to and from facilities outside the U.S. should adhere to HIPAA requirements. Policy also supports reporting and tracking safety and quality data for procedures performed outside the U.S. Substantially similar guidelines were published by the American Society for Metabolic and Bariatric Surgery.

Also in 2008, the Transplantation Society and the International Society of Nephrology jointly developed the Declaration of Istanbul on Organ Trafficking and Transplant Tourism to promote and uphold ethical practice in organ transplantation internationally [20]. The following year, the American College of Surgeons issued a position statement on medical and surgical tourism that supports patients’ right to choose where and from whom they receive care and encourages College Fellows to support informed decision making. The statement advises patients to consider not only medical, but also “social, cultural and legal implications of seeking treatment abroad,” as well as to seek care at an accredited institution and to obtain a complete copy of their medical records before returning to the U.S [36]. In 2013, the International Society for Stem Cell Research similarly issued a critique of commercial stem cell therapy and called for adherence to ethical standards regarding interventions whose clinical value has not yet been demonstrated [24].

Several professional medical organizations have published cautionary information for patients about medical tourism, including the American Academy of Facial and Plastic Surgery [37], the American Society of Hematology [38], the American Society of Plastic Surgery [39], and the American Society for Metabolic and Bariatric Surgery [40].

ETHICAL CHALLENGES OF MEDICAL TOURISM

Medical tourism can leave home country physicians in problematic positions: Faced with the reality that medical tourists often need follow-up when they return, even if only to monitor the course of an uneventful recovery; confronted with the fact that returning medical tourists often don’t have records of the procedures they underwent and the medications they received, or contact information for the foreign health care professionals who provided services; asked to make right what went wrong when patients experience complications as a result of medical travel, often having not been informed about, let alone part of the patient’s decision to seek health care abroad [41].

Many aspects of medical tourism confound core ethical expectations regarding patients’ rights—to informed consent, continuity of care and access to their medical records (E-1.1.3)—and physicians’ responsibilities—to promote quality of care (E-1.1.6) and patient safety (E-8.6), to be prudent stewards of health care resources (E-11.1.2). Patients’ decisions to seek medical care abroad may also threaten trust [41] and the integrity of patient-physician relationships. These challenges are fundamentally systemic, yet patients often expect individual physicians to find ways to address them.
Informed Decision Making

Ensuring that patients make informed decisions about seeking care abroad is not possible unless patients let physicians know they are considering doing so. Expecting physicians to routinely screen patients for possible interest in becoming a medical tourist is not realistic, but when a patient expresses concern about access to certain services, or a desire to receive care that is generally not available in the community, physicians should recognize the possibility that the patient is contemplating going outside the local system of care and explore the patient’s concerns and wishes more fully.

When patients’ responses indicate interest in medical tourism, it is reasonable to expect physicians will help ensure that patients have the information they need to make well-considered decisions. Physicians might do so by addressing the pros and cons of medical tourism themselves when they have relevant knowledge, by referring the patient to a specialist who has relevant expertise, or by directing the patient to other resources on medical tourism for the procedure, such as specialty society or government information pages.

Continuity of Care

Arguably, the extent of individual physicians’ ethical responsibility to provide after care for patients who have undergone a medical procedure abroad as a medical tourist will vary with the circumstances. Physicians have a responsibility to provide urgently needed care, or refer the patient appropriately (Principle VI), and to provide or refer for needed follow-up care when a current patient has received emergency medical care abroad. They are likewise expected to honor contractual obligations to provide care (E-1.1.2).

In other circumstances, however, physicians’ ethical responsibility may be less stringent, particularly when patients have traveled for elective procedures. Physicians have stronger obligations to patients with whom they have a patient-physician relationship, especially one of long standing (E-1.1.7) [8]. Beyond carefully considering the likely effect on the individual patient’s welfare, physicians should take into account whether they have the resources to provide the needed care safely and the likely effects providing care or declining to do so will have on their ability to meet the needs of other patients in their practice (E-1.1.2). Physicians have a further responsibility to reflect on the burden declining to provide follow-up care may impose on fellow professionals (cp. E-1.1.7), and on the likely impact on the health and resources of the community (E-11.1.2).

Preserving Trust

Patients may be hesitant to discuss medical tourism, fearing their physician’s reaction [41]. Physicians have a responsibility to offer their best professional guidance about a patient’s decision to become a medical tourist, just as they would any other decision about care. This includes being candid when they deem a decision to obtain specific care abroad not to be in the patient’s best interests and helping the patient understand why they believe that to be the case. To protect the trust on which an effective therapeutic relationship is grounded, physicians should acknowledge the patient’s goal for seeking care. As patient advocates, they should help ensure that the patient has exhausted options for getting the desired care within their home health care system [42]. This includes encouraging patients who propose to travel for an unapproved therapy to enroll in appropriate clinical trials.

When patients inform them before they travel, physicians should advise the patient about the level of care they will or will not be able or willing to provide when the patient returns (cp. E-1.1.7).
When a patient who did not inform the physician in advance returns seeking follow-up care for
treatment received abroad, physicians must decide whether to provide that care. The obligation of
compassion does not automatically translate into a duty to treat except in an emergency. However,
before declining to provide needed after care to a medical tourist, physicians should carefully
consider the effect that decision is likely to have on the patient’s welfare, other health care
professionals, and the community.

Oversight

The European Union has established formal guidelines for cross-border care among member
countries [43], and entities such as the Joint Commission International and Accreditation Canada
accredit international health care facilities [32], but at present, medical tourism is otherwise
regulated only to the extent that medical practice in individual countries is regulated. Medical
tourism companies as such are not regulated at all. Nor do medical tourism agents receive specific
training or certification [32]. The absence of systematic collection and reporting of data about
outcomes leaves patients, physicians, and health care systems in the dark, impeding informed
decision making about medical tourism and obscuring potential risks to public health. Physicians
have firsthand knowledge of the experience of individual patients who have become medical
tourists and are well positioned to advocate for standards to improve quality of care and protect the
interests of patients who seek care abroad.

RECOMMENDATION

In view of these considerations, the Council on Ethical and Judicial Affairs recommends that the
following be adopted and the remainder of this report filed:

Medical tourists travel to address what they deem to be unmet personal medical needs,
prompted by issues of cost, timely access to services, higher quality of care or perceived
superior services, or to access services that are not available in their country of residence. In
many instances, patients travel on their own initiative, with or without consulting their
physician, and with or without utilizing the services of commercial medical tourism companies.
The care medical tourists seek may be elective procedures, medically necessary standard care,
or care that is unapproved or legally or ethically prohibited in their home system.

Many medical tourists receive excellent care, but issues of safety and quality can loom large.
Substandard surgical care, poor infection control, inadequately screening of blood products,
and falsified or outdated medications in lower income settings of care can pose greater risks
than patients would face at home. Medical tourists also face heightened travel-related risks.
Patients who develop complications may need extensive follow-up care when they return
home. They may pose public health risks to their home communities as well.

Medical tourism can leave home country physicians in problematic positions: Faced with the
reality that medical tourists often need follow-up when they return, even if only to monitor the
course of an uneventful recovery; confronted with the fact that returning medical tourists often
do not have records of the procedures they underwent and the medications they received, or
contact information for the foreign health care professionals who provided services, asked to
make right what went wrong when patients experience complications as a result of medical
travel, often having not been informed about, let alone part of the patient’s decision to seek
health care abroad.
Physicians need to be aware of the implications of medical tourism for individual patients and the community.

Collectively, through their specialty societies and other professional organizations, physicians should:

(a) Support collection of and access to outcomes data from medical tourists to enhance informed decision making.

(b) Advocate for education for health care professionals about medical tourism.

(c) Advocate for appropriate oversight of medical tourism and companies that facilitate it to protect patient safety and promote high quality care.

(d) Advocate against policies that would require patients to accept care abroad as a condition of access to needed services.

Individually, physicians should:

(e) Be alert to indications that a patient may be contemplating seeking care abroad and explore with the patient the individual’s concerns and wishes about care.

(f) Seek to familiarize themselves with issues in medical tourism to enable them to support informed decision making when patients approach them about getting care abroad.

(g) Help patients understand the special nature of risk and limited likelihood of benefit when they desire an unapproved therapy. Physicians should help patients frame realistic goals for care and encourage a plan of care based on scientifically recognized interventions.

(h) Advise patients who inform them in advance of a decision to seek care abroad whether the physician is or is not willing to provide follow-up care for the procedure(s), and refer the patient to other options for care.

(i) Offer their best professional guidance about a patient’s decision to become a medical tourist, just as they would any other decision about care. This includes being candid when they deem a decision to obtain specific care abroad not to be in the patient’s best interests. Physicians should encourage patients who seek unapproved therapy to enroll in an appropriate clinical trial.

(j) Physicians should respond compassionately when a patient who has undergone treatment abroad without the physician’s prior knowledge seeks nonemergent follow-up care. Those who are reluctant to provide such care should carefully consider

(i) the nature and duration of the patient-physician relationship;

(ii) the likely impact on the individual patient’s well-being;

(iii) the burden declining to provide follow-up care may impose on fellow professionals;

(iv) the likely impact on the health and resources of the community.
Physicians who are unable or unwilling to provide care in these circumstances have a responsibility to refer the patient to appropriate services.

(NEW HOD/CEJA POLICY)

Fiscal Note: Less than $500.
REFERENCES

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

Subject: Expanded Access to Investigational Therapies

Presented by: Dennis S. Agliano, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Peter H. Rheinstein, MD, JD, MS, Chair)

Policy D-460.967(2), “Study of the Current Uses and Ethical Implications of Expanded Access Programs,” instructs our American Medical Association (AMA) to “study the ethics of expanded access programs, accelerated approval mechanisms, and payment reform models meant to increase access to investigational therapies, including access for infants and children.” This report by the Council on Ethical and Judicial Affairs (CEJA) examines ethical issues in relation to expanded access and offers guidance for physicians.

ACCESS TO INVESTIGATIONAL THERAPY

For some patients who face serious life-threatening or life-limiting conditions there are few or no approved therapies. For others, existing therapies are unlikely or have failed to be effective. In such situations, patients and their physicians may turn to as yet unapproved treatments as a last hope.

From a societal perspective, participating in a clinical trial is the most desirable way for patients to obtain access to therapies still in development [1,2]. But from the perspective of individual patients, enrolling in a randomized trial cannot guarantee access to the treatment they seek; some will not meet inclusion criteria to be accepted as trial participants even if they are willing to take the chance of being randomized to a control arm rather than the investigational therapy; still others may be unable to participate for other reasons. The expanded access program of the US Food and Drug Administration (FDA) allows patients in such circumstances to seek access to treatment with an investigational therapy outside a clinical trial.

Expanded Access ("Compassionate Use")

“Expanded access” refers “the use of an investigational drug when the primary purpose is to diagnose, monitor, or treat a patient rather than to obtain the kind of information about the drug that is generally derived from clinical trials [3].

Following the thalidomide scandal of the late 1950s and early 1960s, in 1962 the US Congress mandated that the FDA validate the safety and effectiveness of new drugs based on substantial evidence collected from controlled clinical trials, which significantly lengthened the timelines for development of new drugs [4]. The FDA began allowing patients and physicians to petition for access to unapproved drugs [4], and in 1987 recognized “treatment IND [investigational new

* 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
drug) protocols in response to the HIV/AIDS crisis as dying AIDS patients sought access to the then-unapproved drug AZT [5].

With the push from advocacy groups such as ACT UP, the FDA agreed to allow pharmaceutical companies to offer access to other promising AIDS drugs through an “expanded access” (or “compassionate use”) protocol; Alzheimer and cancer patients and their advocates soon followed with similar demands for access to unproven therapies [5]. In 2009, the FDA substantially revised federal regulations (at 21 CFR 312), creating three categories for access to investigational therapies: use by individual patients, use by intermediate-sized patient populations (tens to hundreds), and widespread use after a clinical trial has been successfully completed but prior to FDA approval of the therapy [4,6].

Before a patient can legally receive an investigational therapy outside of a clinical trial, the FDA must approve the expanded access application submitted by the physician who will oversee treatment (21 CFR312.305). To be granted, a request must demonstrate that the patient(s) for whom access is requested has a “serious or immediately life-threatening” condition for which there is no satisfactory alternative therapy; that the potential benefit to the patient justifies the risk of the investigational therapy; and that the potential risks of the investigational therapy “are not unreasonable in the context of the disease or condition to be treated” (21 CFR 312.305). To protect the scientific integrity of clinical trials, it must also be shown that providing the investigational therapy “will not interfere with the initiation, conduct, or completion of clinical investigations that could support marketing approval of the expanded access use or otherwise compromise the potential development of the expanded access use” (21 CFR 312.305).

The regulations further set evidentiary thresholds for risk that are more stringent the greater number of patients involved and the less serious the condition. For single patient use, a physician need only conclude that the investigational therapy poses no greater risk than the disease itself (21 CFR 312.310), while for intermediate-size patient populations, there must be evidence that the drug is safe “at the dose and duration” proposed for expanded access use and that there is “at least preliminary clinical evidence of effectiveness” (or plausible pharmacologic effect) to make use under expanded access “a reasonable therapeutic option” for the intended patient population (21 CFR 312.315). Thus, patients who receive investigational therapies outside clinical trials don’t have the same protections as do enrolled participants, such as monitoring by institutional review boards and data and safety monitoring boards, which can halt trials when significant concerns arise [7]. Because patients receiving investigational therapies under expanded access are not connected to a particular trial site, “the potential for rigorous safety monitoring is greatly reduced” [7].

Under the 2009 regulations, the treating physician must determine that the proposed use meets FDA criteria for expanded access and is also responsible for obtaining IRB approval for use of the investigational therapy for the patient, which can be particularly challenging for physicians outside academic medical centers [4]. Physicians who treat patients with investigational therapies under expanded access must comply with the responsibilities for investigators set out elsewhere in federal regulations governing clinical trials. In 2017, the FDA took steps to streamline the process of applying for expanded access, simplifying the single patient application form and modifying the requirement for IRB approval to allow review by a single member of the IRB rather than the fully convened board [8]. FDA has indicated that further simplification is being considered [8].

Sponsors are not required to provide investigational therapies for use under expanded access, and FDA has no authority to mandate that a drug be made available by an unwilling sponsor [7]. Sponsors decline to participate in expanded access for a variety of reasons, including limited supply of the investigational therapy, limited capacity to produce additional supplies, or the cost of
making the therapy available outside an ongoing clinical trial [1,4]. Sponsors who provide an
investigational therapy under expanded access face additional administrative burdens—among
other requirements, regulations mandate that they ensure that physicians are qualified to administer
the therapy and submit investigational new drug safety reports for the expanded access use,
including reporting adverse events (21 CFR 312.305).

One concern is that adverse events reported for expanded access use may in fact not be associated
with the investigational therapy and could jeopardize development of it [1,9]. Patients who receive
an investigational therapy outside clinical trials may have more advanced disease than trial
participants, have other concurrent medical conditions, or be receiving other concurrent treatment,
which can make it more difficult to determine the cause of an adverse event. Responding to this
concern, the FDA recently clarified expectations for reporting negative effects, permitting sponsors
to report only those events for which “there is evidence to suggest a causal relationship between the
drug and the adverse event” [8].

Impact of Expanded Access

Applications for expanded access use for both drugs and biologics have grown steadily—from just
under 1,100 in 2010 to more than 1,700 in 2016 (with a high total of 1,999 in 2014) [10]. Overall,
the Center for Drug Evaluation and Research received nearly 11,000 applications between 2005
and 2014, of which 99.7% were approved [1]. The majority of requests were in “therapeutic areas
where products were being developed to treat life-threatening illness with significant unmet
medical need,” such as hematologic and solid organ malignancies [1].

Less is known about whether requests for expanded access use are granted by sponsors or whether
investigational therapies provided through expanded access have received FDA approval. A review
of found 398 expanded access programs registered at ClinicalTrials.gov as of July 2016 [11]. Of
the 210 unique experimental drugs for which data were reviewed, 76 percent had ultimately
received approval. As the authors note, this suggests that “we cannot entirely eliminate safety and
efficacy questions in expanded access and compassionate use” [11].

The Future of Expanded Access

Provisions of the 21st Century Cures Act enacted in December 2016 address the challenges patients
and physicians face in obtaining information about investigational therapies that may be available
through expanded access. The act requires manufacturers and distributors of investigational drugs
intended to treat serious diseases to “make public and readily available” their policies for
evaluating and responding to requests for expanded access use (Pub L 114-255). The act further
requires that such policies include contact information for the manufacturer or distributor,
procedures for making requests and general criteria used to evaluate requests for individual
patients, and a link or other reference to clinical trial information about the investigational therapy.
The act does not, however, require a manufacturer or distributor to guarantee access to an
investigational therapy in development.

In addition to simplifying application forms for single patient use and procedures for IRB approval,
in July 2017 FDA launched a new online Expanded Access Navigator in conjunction with the
Reagan-Udall Foundation to assist patients and physicians in finding information about expanded
access [8].
ETHICAL CHALLENGES IN EXPANDED ACCESS

Although ongoing efforts to simplify expanded access programs will likely enable more patients to receive treatment with investigational therapies, ethical concerns remain. Key among them are issues of informed consent and decision making, fairness in access to investigational therapies, and possible negative effects for the conduct of clinical trials.

Informed Consent

Informed consent to medical treatment is fundamental in both ethics and law. Patients have the right to receive information and to ask questions about recommended treatments so that they can make well-considered decisions about care (E-2.1.1). Treatment with an investigational therapy poses special challenges in this regard. Patients who face serious, life-threatening illnesses for which approved therapies have not been effective or for which there are no approved therapies may be particularly vulnerable to holding out false hope for investigational therapy [12]. Promoting truly informed decisions about whether to request expanded access is critical, but can be difficult, both because information about an investigational therapy is often incomplete or difficult to obtain, and because patients may be prone to misinterpreting what information is available.

In the early stages of development, relatively little may be known about an investigational therapy’s efficacy or possible adverse effects [4,13]. Information about therapies still in development is often proprietary and thus not readily available, making it difficult for patients and physicians to assess whether the risk of disease outweighs the risk of the investigational therapy for purposes of requesting expanded access [4]. Moreover, terminally ill patients do not always evaluate risks and benefits objectively—they tend to overestimate likely benefit and underestimate the burdens of as yet unproven therapies [12,14]. They may be under a “therapeutic misconception” and fail to appreciate that the therapy has not been demonstrated to be effective [15], or be “unrealistically optimistic” and expect that their personal outcomes will be more positive than the outcomes of others in similar situations [14,16].

FDA acknowledges that patients who are candidates for expanded access use “are a particularly vulnerable population” and “should be afforded a rigorous informed consent process that effectively communicates the risks and potential benefits of any investigational therapy to be used for treatment use [sic] in a way that does not raise false expectations about a positive outcome from treatment and makes clear what is unknown about the drug” [6]. Expanded access regulations mandate that the treating physician (“investigator” in the language of the regulations) ensure that the consent requirements of the Common Rule are met (21 CFR 305(c)(4)), including informing the patient that the therapy is investigational and that there is uncertainty as to its safety and effectiveness [3].

FDA also mandates that the sponsor of an investigational therapy provide the treating physician “with the information needed to minimize the risk and maximize the potential benefits of the investigational drug (the investigator’s brochure must be provided if one exists for the drug)” (21 CFR 312.305(c)(5)) as a requirement for expanded access use. It is essential that the treating physician have as much information as possible about an investigational therapy to provide appropriate patient care. An investigator’s brochure “provides insight to support the clinical management of the study subject” [17]—or, in the instant case, the patient receiving the investigational therapy under expanded access—by compiling both clinical and nonclinical information about the therapy.
Financial Barriers to Expanded Access

Issues of equity also arise with respect to expanded access programs. Sponsors may provide investigational therapies at no cost for expanded access use, but they are not required to do so. Current FDA regulations permit sponsors to recover direct costs of providing an investigational therapy for expanded access use (21 CFR 312.8(d)(1)), either directly from patients or by billing third-party payers. For the most part, insurance plans do not reimburse the costs of therapies not yet approved for marketing [14,18]. Although most sponsors shoulder the cost burden, when they do not patients may be unable to afford to pay out of pocket, even when they have been approved for expanded access use. It has been argued that expanded access “favors the rich or well-connected” [4].

Effects on Clinical Trials/Implications for Public Health

Expanded access programs may also adversely affect the successful completion of clinical trials and marketing approval of clinical trials. Permitting patients to obtain not yet approved therapies by means of expanded access may delay enrollment in trials of the therapy or jeopardize retention of participants, undermining efforts to demonstrate the safety and efficacy of the investigational therapy [9]. This in turn thwarts society’s interest in the development and approval of new therapies for populations of patients [2,9]. The extent to which expanded access programs in fact have this effect is not clear. Before FDA will approve a request for expanded access use, patients and physicians must demonstrate that the patient is not a candidate for a clinical trial, for example, because the individual fails to meet inclusion criteria or existing trials are geographically inaccessible to the individual.

RECOMMENDATION

In light of these considerations, the Council on Ethical and Judicial Affairs recommends that Policy D-460.967(2), “Study of the Current Uses and Ethical Implications of Expanded Access Programs,” be rescinded, the following be adopted, and the remainder of the report be filed:

Physicians who care for patients with serious, life-threatening illness for whom standard therapies have failed, are unlikely to be effective, or do not exist should determine whether questions about access to investigational therapy through the U.S. Food and Drug Administration’s “expanded access” program are likely to arise in their clinical practice. If so, physicians should familiarize themselves with the program to be better able to engage in shared decision making with patients.

When a patient requests expanded access to an investigational therapy, physicians should:

(a) Assess the patient’s individual clinical situation to determine whether an investigational therapy would be appropriate, including:

(i) whether there is a satisfactory alternative therapy available to diagnose, monitor, or treat the patient’s disease or condition;

(ii) the nature of potential risks of the investigational therapy and whether those risks are not unreasonable in the context of the patient’s disease or condition;

(iii) whether the potential benefit to the patient justifies the risks of the investigational therapy;
(iv) whether the patient meets inclusion criteria for an existing clinical trial of the investigational therapy.

(b) As part of the informed consent process, advise the patient (or parent/guardian if the patient is a minor) that the investigational therapy has not yet been demonstrated to be effective in treating the patient’s condition and may pose as yet unknown risks. Physicians should explain the importance of clinical trials, encourage patients who meet inclusion criteria to participate in an existing trial rather than seek access to investigational therapy through the FDA expanded access program, and direct patients who wish to participate in research to appropriate resources.

(c) Decline to support an application for expanded access to an investigational therapy when:

(i) the physician judges the treatment with the investigational therapy not to be in the patient’s best interest, and explain why; or

(ii) the physician does not have appropriate resources and ability to safely supervise the patient’s care under expanded access.

In such cases, physicians should refer the patient to another physician with whom to discuss possible application for expanded access.

(d) Discuss the implications of expanded access for the patient and family and help them form realistic expectations about what it will mean to be treated with the investigational therapy outside a clinical trial. Physicians should alert patients:

(i) to the possibility of financial or other responsibilities associated with receiving an investigational therapy through expanded access;

(ii) to the lack of infrastructure to systematically monitor and evaluate the effects of the investigational therapy outside a clinical trial;

(iii) that they need information about how to contact the manufacturer for guidance if they seek emergency care from a health care professional who is not affiliated with a clinical trial of the investigational therapy;

(iv) that the physician has a responsibility to collect and share clinical information about the patient’s course of treatment with the investigational therapy, as well as to report any adverse events that may occur over the course of treatment;

(v) to the conditions under which the physician would recommend stopping treatment with the investigational therapy.

(NEW HOD/CEJA POLICY)

Fiscal Note: Less than $500
REFERENCES


REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 5-A-18

Subject: Study Aid-in-Dying as End-of-Life Option
(Resolution 15-A-16)
The Need to Distinguish “Physician-Assisted Suicide” and “Aid in Dying”
(Resolution 14-A-17)

Presented by: Dennis S. Agliano, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Peter H. Rheinstein, MD, JD, MS, 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 and its Council on Judicial and Ethical Affairs, 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 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 (CEJA) 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.

* 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.
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 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 to 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), 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].

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 [4], 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 irredicibly 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 [5]—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 [5,6], and to leave space open for ongoing discussion. Nonetheless, as a policy position, studied neutrality has been criticized 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 [7].

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” [8].

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 [8]. 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” [9].

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” [10], others question whether the available data can in fact support any such conclusions, finding the evidence cited variously flawed [11], inadequate [12], or distorted [13].

Although cross-cultural comparisons are problematic [14], 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 [15]. 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” [16].

Studies have also raised questions about how effective retrospective review of decisions to provide euthanasia/assisted suicide is in policing practice [17,18]. 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 [17]. 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]” [18]. 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” [19]. 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 [20,21].

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” [15].

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 [22]. They are concerns echoed in a February 2018 workshop on physician-assisted death convened by the National Academies of Science, Engineering and Medicine [23]. They underscore how important it is to understand why a patient requests assisted suicide as a starting point for care.

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 [4,24]. 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 [25]. The profession also has a responsibility to advocate for adequate resources for end-of-life care [14,25], 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” [24]. 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.

RECOMMENDATION

Over the past two years, 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. After careful consideration, CEJA concludes that in its current form 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. The Council on Ethical and Judicial Affairs therefore 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.
REFERENCES


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

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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2008 POLICIES

In this report, the Council on Ethical and Judicial Affairs presents its recommendations regarding the disposition of 2008 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 2008. 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 2008, 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

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<tr>
<th>Policy No.</th>
<th>Title</th>
<th>Recommended Action &amp; Rationale</th>
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| H-160.998 | Health Care Dignity and Self Respect | Rescind: Policies have been superseded by the following:  
  - H-165.838 Health System Reform Legislation  
  - H-165.888 Evaluating Health System Reform Proposals  
  - H-165.920 Individual Health Insurance |
| H-230.962 | Subspecialists Functioning as Primary Care Physicians | Retain: Policy remains relevant; edit to remain timely  
It is the policy of the AMA that clinical privileges in primary care be granted to physicians that have demonstrated capability through education, training, experience and current competence, and that the practice of managed care organizations to arbitrarily deny denying primary care privileges to physicians because of subspecialty or second specialty training be opposed by the AMA. |
| H-315.981 | Privacy of a Physician's Personal Medical Records | Retain: Policy remains relevant. |
| H-35.999 | Medicine and Pharmacy Relations | Retain: Policy remains relevant |
| H-350.971 | Initiatives Regarding Minorities  
   Improving Healthcare of Hispanic Populations in the United States | Defer recommendation to 2018  
Interim meeting pending report on consolidation of AMA policy addressing issues of disparities and the health of minority populations: |
<table>
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<tr>
<th>Code</th>
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<tr>
<td>H-160.991</td>
<td>Health Care Needs of Gay, Lesbian, Bisexual and Transgender Populations</td>
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<tr>
<td>H-295.878</td>
<td>Eliminating Health Disparities—Promoting Awareness and Education of Lesbian, Gay, Bisexual and Transgender (LGBT) Issues in Medical Education</td>
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<tr>
<td>H-350.957</td>
<td>Addressing Immigrant Health Disparities</td>
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<td>H-350.958</td>
<td>Hispanic Population and Access to the US Healthcare System</td>
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<td>Guiding Principles for Eliminating Racial and Ethnic Health Care Disparities</td>
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<td>H-350.961</td>
<td>Improving the Health of Minority Populations</td>
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<td>H-350.966</td>
<td>Health Initiatives on Asian-Americans and Pacific Islanders</td>
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<tr>
<td>H-350.971</td>
<td>AMA Initiatives Regarding Minorities</td>
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<tr>
<td>H-350.972</td>
<td>Improving the Health of Black and Minority Populations</td>
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<td>H-350.974</td>
<td>Racial and Ethnic Disparities in Health Care</td>
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<td>H-350.976</td>
<td>Improving Health Care of American Indians</td>
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<tr>
<td>H-440.869</td>
<td>Establishment of State Commission/Task Force to Eliminate Racial and Ethnic Health Care Disparities</td>
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<tr>
<td>D-350.996</td>
<td>Strategies for Eliminating Minority Health Care disparities</td>
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<tr>
<td>D-55.997</td>
<td>Cancer and Health Care Disparities among Minority Women</td>
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<td>H-350.978</td>
<td>Minorities in the Health Professions</td>
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<td>H-370.967</td>
<td>Ethical Procurement of Organs for Transplantation</td>
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<td>D-478.992</td>
<td>Health Information Technology Purchasing Guidance</td>
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D-65.995 Health Care Disparities among Gay, Lesbian, Bisexual and Transgender Families
WHEREAS, President Trump’s administration has created a new conscience and religious freedom division within the Health and Human Services department, with the intent of allowing all health professionals to opt out of providing services that violate their moral or religious beliefs; and

WHEREAS, The Acting Health and Human Services Secretary Eric D. Hargan has stated that the creation of this office, “represents a rollback of polices that had prevented many Americans from practicing their profession and following their conscience at the same time, and that Americans of faith should feel at home in our health system, not discriminated against, and that states should have the right to take reasonable steps in overseeing their Medicaid programs, and being good stewards of public funds”; and

WHEREAS, A number of women’s groups, LGBT rights groups and physicians have expressed that the creation of this office and policy would further discriminate against vulnerable populations and worsen inequities within the health care system; and

WHEREAS, To impose a broad religious refusal policy that will allow individuals and institutions to deny basic care for women, transgender people and people of diverse ethnic backgrounds; and

WHEREAS, This policy reverses years of policies that have been put in place under previous administrations that had narrowed conscience protections; and

WHEREAS, This new office and policy appears to go against the oath that health care providers take when they enter their professions, to provide basic care to those who need it; and

WHEREAS, The MSSNY Committee on Health Disparities believes that religious liberty gives a person the right to their beliefs, but it does not give a person the right to impose those beliefs on others, or harm others, including by discriminating against others; therefore be it

RESOLVED, That our American Medical Association speak against policies that are discriminatory and create even greater health disparities in medicine (Directive to Take Action); and be it further

RESOLVED, That our AMA be a voice for our most vulnerable populations, including sexual, gender, racial and ethnic minorities, who will suffer the most under such policies, further widening the gaps that exist in health and wellness in our nation. (Directive to Take Action)
RELEVANT AMA POLICY

Racial and Ethnic Disparities in Health Care H-350.974
1. Our AMA recognizes racial and ethnic health disparities as a major public health problem in the United States and as a barrier to effective medical diagnosis and treatment. The AMA maintains a position of zero tolerance toward racially or culturally based disparities in care; encourages individuals to report physicians to local medical societies where racial or ethnic discrimination is suspected; and will continue to support physician cultural awareness initiatives and related consumer education activities. The elimination of racial and ethnic disparities in health care an issue of highest priority for the American Medical Association.

2. The AMA emphasizes three approaches that it believes should be given high priority:
   A. Greater access - the need for ensuring that black Americans without adequate health care insurance are given the means for access to necessary health care. In particular, it is urgent that Congress address the need for Medicaid reform.
   B. Greater awareness - racial disparities may be occurring despite the lack of any intent or purposeful efforts to treat patients differently on the basis of race. The AMA encourages physicians to examine their own practices to ensure that inappropriate considerations do not affect their clinical judgment. In addition, the profession should help increase the awareness of its members of racial disparities in medical treatment decisions by engaging in open and broad discussions about the issue. Such discussions should take place in medical school curriculum, in medical journals, at professional conferences, and as part of professional peer review activities.
   C. Practice parameters - the racial disparities in access to treatment indicate that inappropriate considerations may enter the decision making process. The efforts of the specialty societies, with the coordination and assistance of our AMA, to develop practice parameters, should include criteria that would preclude or diminish racial disparities.

3. Our AMA encourages the development of evidence-based performance measures that adequately identify socioeconomic and racial/ethnic disparities in quality. Furthermore, our AMA supports the use of evidence-based guidelines to promote the consistency and equity of care for all persons.

4. Our AMA: (a) actively supports the development and implementation of training regarding implicit bias, diversity and inclusion in all medical schools and residency programs; (b) will identify and publicize effective strategies for educating residents in all specialties about disparities in their fields related to race, ethnicity, and all populations at increased risk, with particular regard to access to care and health outcomes, as well as effective strategies for educating residents about managing the implicit biases of patients and their caregivers; and (c) supports research to identify the most effective strategies for educating physicians on how to eliminate disparities in health outcomes in all at-risk populations.

Whereas, The Family and Medical Leave Act (FMLA) requires employers with 50 or more employees to grant up to 12 weeks of unpaid annual leave to allow workers to care for a spouse, child, or parent (except in-laws) with a serious health condition, to take leave for personal health conditions, or to care for newly born or adopted children;¹ and

Whereas, LGBT persons report poorer health as compared to their heterosexual counterparts, including earlier age at disability, increased risk of sexually transmitted infection among MSM, decreased likelihood to obtain preventive cervical cancer screening among lesbian women, and increased incidence of obesity among lesbian and bisexual women;²,³,⁴,⁵ and

Whereas, Results from the 2008 National Health Interview Survey indicated workers with paid leave are significantly more likely to see healthcare providers and to receive preventative screenings independent of insured or uninsured status and health status;⁶ and

Whereas, In 2016, a study from the American Journal of Orthopsychiatry asserted that affirming the chosen family of LGBT individuals in family and medical leave policies improved mental well-being;⁷ and

Whereas, In 2010, the United States Office of Personnel Management issued regulations to modify its definitions of family member and immediate relative to include “domestic partner and parents thereof” and “any individual related by blood or affinity whose close association with the employee is the equivalent of a family relationship” in order to expand the categories of individuals for whom an employee may use leave;⁸ and

Whereas, Arizona⁹, the District of Columbia¹⁰, Hawaii¹¹, Maine¹², New York¹³, and Oregon¹⁴ have expanded upon the federal FMLA regulations in favor of the “blood or affinity” model,
which allows FMLA-equivalent benefits for chosen family, domestic partners, and individuals who are dependent or mutually interdependent on the employed individual; therefore be it

RESOLVED, That our American Medical Association advocate that Family and Medical Leave Act policies include any individual related by blood or affinity whose close association with the employee is the equivalent of a family relationship. (New HOD Policy)

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

Received: 04/26/18

RELEVANT AMA POLICY:

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

Clarification of Medical Necessity for Treatment of Gender Dysphoria H-185.927
Our AMA: (1) recognizes that medical and surgical treatments for gender dysphoria, as determined by shared decision making between the patient and physician, are medically necessary as outlined by generally-accepted standards of medical and surgical practice; and (2) will advocate for federal, state, and local policies to provide medically necessary care for gender dysphoria. Res. 05, A-16

Health Care Disparities in Same-Sex Partner Households H-65.973
Our American Medical Association: (1) recognizes that denying civil marriage based on sexual orientation is discriminatory and imposes harmful stigma on gay and lesbian individuals and couples and their families; (2) recognizes that exclusion from civil marriage contributes to health care disparities affecting same-sex households; (3) will work to reduce health care disparities among members of same-sex households including minor children; and (4) will support measures providing same-sex households with the same rights and privileges to health care, health insurance, and survivor benefits, as afforded opposite-sex households. CSAPH Rep. 1, I-09 BOT Action in response to referred for decision Res. 918, I-09: Reaffirmed in lieu of Res. 918, I-09 BOT Rep. 15, A-11 Reaffirmed in lieu of Res. 209, A-12

Health Disparities Among Gay, Lesbian, Bisexual and Transgender Families D-65.995
Whereas, The Health Insurance Portability and Accountability Act (HIPAA) placed “limitations on the sale of medical information to third parties for marketing purposes” and prevents medical information from being disclosed unless permitted or required;¹,²,³ and

Whereas, Secondary use of health data entails the use of protected health information (PHI) outside of direct healthcare delivery including strictly commercial activities;¹ and

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

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

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

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

Whereas, In US courts, transactions involving de-identified patient data irrespective of their purpose have come to be labeled as expressions of free speech;¹¹,¹² and
Whereas, PHI ownership rights, whether it be the patient, provider, government or another entity, is unclear and has yet to be formally settled; and

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

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

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

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

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

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

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

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

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

Date Received: 04/26/18


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Whereas, There were 3200 gender confirmation surgeries performed in 2016 in the United States, which represents a 20% increase from the previous year;¹ and

Whereas, Gender confirmation surgeries include a variety of surgical procedures such as transfeminine and transmasculine genital reconstruction, breast surgery, and facial reconstruction;² and

Whereas, While numerous safe and reliable surgical options exist for patients undergoing gender confirmation surgery, there is currently no standard for patient selection and education about the various techniques available;³,⁴ and

Whereas, Patient-reported outcomes are emerging as a standard in the evaluation of and research into surgical quality and outcomes;⁵ and

Whereas, A questionnaire that assesses a patient’s perspective on their physical, sexual, and social well-being following breast reconstructive surgery has been validated for use in assessing procedure outcomes and quality;⁶ and

Whereas, Current research in gender confirmation surgery outcomes utilizes patient questionnaires related to sexual function and bowel and urinary issues that were not originally designed for the transgender population;⁷ and

Whereas, Information gathered from patient-reported outcomes could improve techniques used by surgeons, provide better training, and help new patients better understand how these operations impact overall well-being and quality of life;⁸ therefore be it

RESOLVED, That our American Medical Association support initiatives and research to establish standardized protocols for patient selection, surgical management, and preoperative and postoperative care for transgender patients undergoing gender confirmation surgeries (New HOD Policy); and be it further

RESOLVED, That our AMA support development and implementation of standardized tools, such as questionnaires to evaluate outcomes of gender confirmation surgeries. (New HOD Policy)

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

Received: 04/26/18

RELEVANT AMA POLICY:

Removing Financial Barriers to Care for Transgender Patients H-185.950
Our AMA supports public and private health insurance coverage for treatment of gender dysphoria as recommended by the patient's physician.
Citation: Res. 122; A-08; Modified: Res. 05, A-16;

See also:
H-160.991 Health Care Needs of Lesbian Gay Bisexual and Transgender Populations
H-460.907 Encouraging Research Into the Impact of Long-Term Administration of Hormone Replacement Therapy in Transgender Patients
D-345.994 Increasing Detection of Mental Illness and Encouraging Education
AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 005
(A-18)

Introduced by: Medical Student Section

Subject: Decreasing Sex and Gender Disparities in Health Outcomes

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Peter H. Rheinstein, MD, JD, MS, Chair)

Whereas, Numerous studies have demonstrated the widespread existence of sex and gender bias and disparities in the provision and outcomes of health care, and that awareness of gender bias does not negate its effect;1,2,3,4,5,6,7,8 and

Whereas, These disparities have been attributed to provider bias, physiologic and pathophysiologic sex differences, or a combination of both;1,4,9,10 and

Whereas, Patients with a feminine gender identity or presentation are at risk for gender-bias in health care regardless of biological sex;6,8 and

Whereas, Gender disparities exist in treatments, invasive therapies, referral patterns and wait times which often leads to worsened outcomes including increased mortality rates;1-4,6 and

Whereas, Clinical Decision Support (CDS) tools, which provide electronic alerts and computerized order sets, are recognized methods to minimize gender bias and decrease disparities through automatization of treatment and diagnostic protocols;10,11,12,13,14 and

Whereas, The AMA’s Commission to End Health Care Disparities sought “to ensure equitable, appropriate, effective, safe, and high quality care for all, with no gaps in services based on any medically irrelevant factor;” yet conclusions from the Commission refer only to racial and ethnic disparities;15 and

Whereas, The Council on Ethical and Judicial Affairs recommended in 1991 encouraging the development and implementation of procedures and techniques that preclude or minimize the negative impact of gender bias;13 and

Whereas, A 2016 report from the AMA’s Council on Science and Public Health acknowledged both biological and social factors leading to disparities in women’s health, but only suggested improving medical education and including women in clinical research as solutions;14 and

Whereas, The AMA has existing policy declaring a commitment to eliminating health care disparities with a specific mention of racial and ethnic health disparities, but does not have a policy directly targeting gender-based health care disparities;12 therefore be it

RESOLVED, That our American Medical Association encourage the use of guidelines, treatment protocols, and decision support tools specific to biological sex for conditions in which physiologic and pathophysiologic differences exist between sexes (New HOD Policy); and be it further

RESOLVED, That our AMA support the use of gender-neutral decision support tools that aim to mitigate gender bias in diagnosis and treatment. (New HOD Policy)

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

Received: 04/26/17

RELEVANT AMA POLICY

D-478.995 National Health Information Technology
H-350.971 AMA Initiatives Regarding Minorities
D-350.995 Reducing Racial and Ethnic Disparities in Health Care
An Expanded Definition of Women’s Health H-525.976
Medical Education and Training in Women’s Health H-295.890
Sex and Gender Differences in Medical Research H-525.988
8.5 Disparities in Health Care
Principles of the Patient-Centered Medical Home H-160.919
Medicare Physician Payment Reform D-390.961
Whereas, Living donor organ transplantation is often the best and most cost effective treatment option for patients with end stage organ failure; and

Whereas, Living organ donors have faced discrimination in obtaining life, disability, and long-term care insurance due to company policy prohibitions, coverage denial, or premium price increases; and

Whereas, Clarification is needed regarding live organ donation surgery in qualifying as a serious health condition under the Family Medical Leave Act; and

Whereas, Educational materials on the benefits of live organ donation are not universally available; and

Whereas, The “Living Donor Protection Act of 2017” (HR 1270) addresses each of these burdens related to living organ donation; and

Whereas, Transplant professional and patient-centered organizations have publicly supported the Living Donor Protection Act of 2017; therefore be it

RESOLVED, That our American Medical Association strongly and actively support the Living Donor Protection Act of 2017 (HR 1270). (Directive to Take Action)


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

Received: 04/27/18
Whereas, Self-induced abortion involves women attempting to induce abortion without medical assistance; and

Whereas, Laws criminalizing self-induced abortion increase health risks and deter patients from seeking necessary healthcare services related to self-induced abortion or miscarriage; and

Whereas, Laws criminalizing patients who self-induce abortion lead to increased suspicion towards patients presenting to healthcare providers for miscarriage; and

Whereas, From the beginning of 2011 through July 2016, states enacted 334 new legal restrictions on abortion, further limiting access to abortion care. In 2018 alone, 695 provisions have already been introduced to further restrict abortion; and

Whereas, National studies of abortion patients have shown that approximately 2% of patients attempted to self-induce an abortion at some point in their lives. That number is higher in states such as Texas with stricter legal restrictions on abortion, where one study showed that 7% of patients attempted some method to end their pregnancy before presenting to the clinic; and

Whereas, Google search trends from 2005 and 2015 have shown a relative increase in searches for self-induced abortion that correlate with state-based abortion restrictions; and

Whereas, There were more than 700,000 Google searches looking into self-induced abortions in 2015; and

Whereas, A recent online study of 1,235 people who google searched “self-abortion” revealed that almost three-quarters (73%) indicated that they were searching for information because they were pregnant and did not or may not want to be; and

Whereas, Self-induced abortion is significantly associated with post-abortion complications, maternal morbidity and mortality; and

Whereas, The ability and willingness to access medical care if complications relating to self-induced abortion arise are essential for patient safety; and

Whereas, People of color are disproportionately targeted for prosecution and criminalization related to pregnancy outcomes; and
Whereas, The American College of Obstetricians and Gynecologists (ACOG) has taken a very strong position that women should not be prosecuted for trying to end their own pregnancies. ACOG additionally opposes forcing physicians to share information about patients due to its burdensome interference in the patient-provider relationship; therefore be it

RESOLVED, That our American Medical Association oppose the criminalization of self-induced abortion as it increases patients’ medical risks and deters patients from seeking medically necessary services (New HOD Policy); and be it further

RESOLVED, That our AMA advocate against any legislative efforts to criminalize self-induced abortion. (New HOD Policy)

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

Received: 05/01/18

References:
3. ibid.

Relevant AMA Policy:
- Right to Privacy in Termination of Pregnancy H-5.993
- Pregnancy Termination H-5.983
- Opinion 4.2.7 Abortion
- H-5.995 Abortion
- H-160.946 The Criminalization of Health Care Decision Making
Whereas, Some states require parental consent or parental notice for pregnant minors to receive prenatal care tests and procedures such as prenatal genetic testing, epidural block and cesarean section; and

Whereas, In some cases, states allow only certain groups of minors--such as those who are married or already parents--to consent to related prenatal care tests and procedures; and

Whereas, Four states (Kansas, Nevada, New Hampshire, West Virginia) allow a minor who is considered “mature” to consent to related prenatal care tests and procedures; and

Whereas, One state (North Dakota) allows a minor to consent to prenatal care during the first trimester while requiring parental consent for prenatal care during the second and third trimesters; and

Whereas, Thirteen states (Arizona, Connecticut, Indiana, Iowa, Louisiana, Maine, Nebraska, Ohio, Rhode Island, South Dakota, Vermont, Wisconsin, and Wyoming) have no relevant policy or case law regarding minors’ authority to consent to prenatal care; and

Whereas, In some states, such as Indiana and Ohio, without relevant policy or case law, people under age 18 who are in labor cannot consent to their own health care or anything considered to be elective, such as an epidural block; and

Whereas, An epidural block is the most common type of pain relief used for childbirth in the United States; and

Whereas, There are reports of parents withholding consent for interventions such as epidural blocks as a form of punishment for minors becoming pregnant, and

Whereas, Current AMA policy does not oppose restrictions on consent-related rights; therefore be it

RESOLVED, That our American Medical Association work with appropriate stakeholders to support legislation allowing pregnant minors to consent to related tests and procedures from the prenatal stage through postpartum care (Directive to Take Action); and be it further

RESOLVED, That our AMA oppose any law or policy that prohibits a pregnant minor to consent to prenatal and other pregnancy related care, including, but not limited to, prenatal genetic testing, epidural block, and Cesarean section. (Directive to Take Action)
Fiscal note: Modest - between $1,000 - $5,000.

Received: 05/01/18

References:
4. Medications for Pain Relief during Labor and Delivery. Available at https://www.acog.org/Patients/FAQs/Medications-for-Pain-Relief-During-Labor-and-Delivery#what.

Relevant AMA Policy:

Confidential Health Services for Adolescents H-60.965

Our AMA:
(1) reaffirms that confidential care for adolescents is critical to improving their health;
(2) encourages physicians to allow emancipated and mature minors to give informed consent for medical, psychiatric, and surgical care without parental consent and notification, in conformity with state and federal law;
(3) encourages physicians to involve parents in the medical care of the adolescent patient, when it would be in the best interest of the adolescent. When, in the opinion of the physician, parental involvement would not be beneficial, parental consent or notification should not be a barrier to care;
(4) urges physicians to discuss their policies about confidentiality with parents and the adolescent patient, as well as conditions under which confidentiality would be abrogated. This discussion should include possible arrangements for the adolescent to have independent access to health care (including financial arrangements);
(5) encourages physicians to offer adolescents an opportunity for examination and counseling apart from parents. The same confidentiality will be preserved between the adolescent patient and physician as between the parent (or responsible adult) and the physician;
(6) encourages state and county medical societies to become aware of the nature and effect of laws and regulations regarding confidential health services for adolescents in their respective jurisdictions. State medical societies should provide this information to physicians to clarify services that may be legally provided on a confidential basis;
(7) urges undergraduate and graduate medical education programs and continuing education programs to inform physicians about issues surrounding minors' consent and confidential care, including relevant law and implementation into practice;
(8) encourages health care payers to develop a method of listing of services which preserves confidentiality for adolescents; and
(9) encourages medical societies to evaluate laws on consent and confidential care for adolescents and to help eliminate laws which restrict the availability of confidential care.

Citation: (CSA Rep. A, A-92; Reaffirmed by BOT Rep. 24, A-97; Reaffirmed by BOT Rep. 9, A-98; Reaffirmed: Res. 825, I-04; Reaffirmation A-08; Reaffirmed: CMS Rep. 2, I-14)

See also:
2.2.1 Pediatric Decision Making
2.2.2 Confidential Health Care for Minors
AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 009
(A-18)

Introduced by: Women Physicians Section

Subject: Improving and Increasing Clarity and Consistency Among AMA Induced Abortion Policies

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Peter H. Rheinstein, MD, JD, MS, Chair)

Whereas, In recent years our AMA has affirmed the medical relevance of induced abortion; and

Whereas, There are several AMA policies that are directly or indirectly related to induced abortion; and

Whereas, Amendments and revisions of policies have sometimes resulted in use of imprecise and inconsistent language; and

Whereas, This may result in inaccurate perceptions, and reporting of AMA policies on induced abortion; and

Whereas, A review of these policies reveals language inconsistencies that cause AMA policy misunderstandings by the public, as evidenced in the need for and premise for policy H-5.988, “Accurate Reporting on AMA Abortion Policy”; and

Whereas, Legal induced abortion is defined by the Centers for Disease Control and Prevention (CDC), for the purpose of CDC surveillance, as an intervention performed by a specially trained and licensed clinician (e.g., a physician, nurse-midwife, nurse practitioner, or physician assistant) that is intended to terminate an ongoing pregnancy; and

Whereas, The AMA has previously only recognized abortion performed by duly licensed physicians; and

Whereas, In certain states, other licensed and specially trained clinicians perform abortion; and

Whereas, The American College of Obstetricians and Gynecologists encourages expanding the trained pool of non-obstetrician-gynecologist providers to include family physicians, nurse practitioners, physician assistants, and certified nurse-midwives, thereby supporting access to safe abortion care; and

Whereas, Clinical evidence suggests that outcomes are equivalent between physician and other trained clinicians; therefore be it

RESOLVED, That our American Medical Association review its policies on abortion to ensure use of appropriate terminology and that such policies are reflective of appropriate practice standards (Directive to Take Action); be it further
RESOLVED, That AMA Policy H-5.988, “Accurate Reporting on AMA Abortion Policy,” be amended by addition to read as follows:

Accurate Reporting on AMA Abortion Policy H-5.988
Our AMA House of Delegates (HOD) cautions members of the Board of Trustees, Councils, employees and members of the House of Delegates HOD to precisely state current AMA policy on abortion and related issues in an effort to minimize public misperception of AMA policy and urges that our AMA continue efforts to refute misstatements and misquotes by the media with reference to AMA abortion policy.

(Amend HOD Policy)

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

Received: 05/01/18

References:

RELEVANT AMA POLICY

Accurate Reporting on AMA Abortion Policy H-5.988
Our AMA HOD cautions members of the Board of Trustees, Councils, employees and members of the House of Delegates to precisely state current AMA policy on abortion and related issues in an effort to minimize public misperception of AMA policy and urges that our AMA continue efforts to refute misstatements and misquotes by the media with reference to AMA abortion policy.

Citation: (Sub. Res. 21, A-91; Reaffirmed: Sunset Report, I-01; Reaffirmed: CEJA Rep. 8, A-11)

Pregnancy Termination H-5.983
The AMA adopted the position that pregnancy termination be performed only by appropriately trained physicians (MD or DO).

Citation: (Res. 520, A-95; Reaffirmed: CSA Rep. 8, A-03; Modified: CSAPH Rep. 1, A-13)

Freedom of Communication Between Physicians and Patients H-5.989
It is the policy of the AMA: (1) to strongly condemn any interference by the government or other third parties that causes a physician to compromise his or her medical judgment as to what information or treatment is in the best interest of the patient;

(2) working with other organizations as appropriate, to vigorously pursue legislative relief from regulations or statutes that prevent physicians from freely discussing with or providing information to patients about medical care and procedures or which interfere with the physician-patient relationship;

(3) to communicate to HHS its continued opposition to any regulation that proposes restrictions on physician-patient communications; and

(4) to inform the American public as to the dangers inherent in regulations or statutes restricting communication between physicians and their patients.

Citation: (Sub. Res. 213, A-91; Reaffirmed: Sub. Res. 232, I-91; Reaffirmed by Rules & Credentials Cmt., A-96; Reaffirmed by Sub. Res. 133 and BOT Rep. 26, A-97; Reaffirmed by Sub. Res. 203 and 707, A-98; Reaffirmed: Res. 703, A-00; Reaffirmed in lieu of Res. 823, I-07; Reaffirmation I-09; Reaffirmation: I-12; Reaffirmed in lieu of Res. 5, I-13)

See also: Policy on Abortion H-5.990; Right to Privacy in Termination of Pregnancy H-5.993; Abortion H-5.995; E-4.2.7 Abortion; E-4.1.2 Genetic Testing for Reproductive Decision Making
Whereas, Recent data demonstrate that significant differences in salary and compensation exist between male and female physicians, despite improvements in explicit gender discrimination; and

Whereas, Women physicians in academic medicine and in practice earn less than men even after adjustment for factors such as age, years of experience, specialty, reported work hours, clinical productivity, research productivity, and faculty rank; and

Whereas, A recently published analysis of salary differences at 24 US public medical schools found that the annual salaries of female physicians were $19,879 (8%) lower than the salaries of male physicians; this difference persisted through all faculty ranks; and

Whereas, This gender compensation gap is likely to only widen over the course of a woman’s career; and

Whereas, Explicit gender bias in academic medicine has largely decreased since the passage of the Education Amendment to the Civil Rights Act (Title IX), however implicit biases persist and cultural stereotypes continue to disadvantage women in male dominated fields; therefore

RESOLVED, That our American Medical Association advocate for institutional and departmental policies that promote transparency in defining the criteria for initial and subsequent physician compensation (New HOD Policy); and be it further

RESOLVED, That our AMA advocate for equal base pay based on objective criteria (New HOD Policy); and be it further

RESOLVED, That our AMA advocate for implicit bias and compensation determination training for those in positions to determine salary and bonuses, with a focus on how subtle differences in the evaluation of male and female physicians may impede compensation and career advancement (New HOD Policy); and be it further

RESOLVED, That our AMA encourage a specified approach, sufficient to identify gender disparity, to oversight of compensation models, metrics, and actual total compensation for all employed physicians (New HOD Policy); and be it further

RESOLVED, That our AMA establish educational programs to help empower all genders to negotiate equitable compensation. (Directive to Take Action)
Fiscal Note: Not yet determined

Received: 05/01/18

1 Association of Women Surgeons. Association of Women Surgeons Statement on Gender Salary Equity. Available at: www.womensurgeons.org/. Accessed 2/14/18/

RELEVANT AMA POLICY

Gender Disparities in Physician Income and Advancement D-200.981

Our AMA:

(1) encourages medical associations and other relevant organizations to study gender differences in income and advancement trends, by specialty, experience, work hours and other practice characteristics, and develop programs to address disparities where they exist;

(2) supports physicians in making informed decisions on work-life balance issues through the continued development of informational resources on issues such as part-time work options, job sharing, flexible scheduling, reentry, and contract negotiations;

(3) urges medical schools, hospitals, group practices and other physician employers to institute and monitor transparency in pay levels in order to identify and eliminate gender bias and promote gender equity throughout the profession;

(4) will collect and publicize information on best practices in academic medicine and non academic medicine that foster gender parity in the profession; and

(5) will provide training on leadership development, contract and salary negotiations and career advancement strategies, to combat gender disparities as a member benefit.

Citation: (BOT Rep. 19, A-08; Reaffirmed: CCB/CLRPD Rep. 4, A-13)
Whereas, The American Medical Association and AMA’s Women Physicians Section have made concerted efforts to highlight the disparity of physician payment by gender in the United States today, and to increase the influence of women physicians in leadership roles in medicine;¹ and

Whereas, In 2015, while women comprised 34% of the active physician workforce in the United States, and an estimated 46% of all physicians-in-training as well as more than half of all medical students are women, much remains to be done to improve equity and parity among physician payment and to increase opportunities for promotion and leadership;² and

Whereas, Studies have historically found a payment disparity gap among male and female physicians within the same specialty,³ and this payment disparity continues to exist in all specialties of medicine in 2018;⁴ and

Whereas, Among cohorts of equal training and experience, adjusting for variables including workhours, calls, vacation, gender, academic versus non-academic practice, women held less advanced academic positions, earning significantly less compensation ten years after graduation;⁵ and

Whereas Significant differences in salary also exist among male and female physicians with faculty appointments at U.S. public medical schools, even after accounting for age, experience, specialty faculty rank, and measures of research productivity and clinical revenue;⁶ and

Whereas, Female physicians in early and mid-career may opt for flexibility in schedules in their child-bearing and child-rearing years; and

Whereas, The U.S. will face a significant shortage of physicians, fueled by population growth, an increase in the number of aging Americans, and retirement of practicing doctors, a shortage of between 40,800 and 104,900 physicians by 2030⁷ and the AMA has prioritized confronting this shortage in previous AMA House of Delegates meetings;⁸ and

Whereas, The city of Chicago can no longer ask about salary history on employment applications, part of a growing effort nationwide to improve pay equality between men and women;⁹ and

Whereas, On January 29, 2009 the Lilly Ledbetter Fair Pay Act was signed into law to reinforce the protection against pay discrimination under the Equal Pay Act of 1963 (EPA), which prohibits sex-based wage discrimination between men and women in the same establishment
who perform jobs that require substantially equal skill, effort, and responsibility under similar working conditions; therefore be it

RESOLVED, That our American Medical Association, together with the assistance of professional medical societies, create an awareness campaign to inform physicians about their rights under the Lilly Ledbetter Fair Pay Act and Equal Pay Act (Directive to Take Action); and be it further

RESOLVED, That our AMA, together with the assistance of professional medical societies, help U.S. public medical schools and facilities create guidance for institutional transparency of compensation, and regular gender-based pay audits, in order to narrow the gender inequity in pay and promotion (Directive to Take Action); and be it further

RESOLVED, That our AMA recommend to eliminate the question of prior salary information from job applications for physician recruitment in academic and private practice. (Directive to Take Action)

Fiscal Note: Not yet determined

Received: 05/02/18

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1 American Medical Association: https://www.ama-assn.org/about/women-physicians-section-wps

RELEVANT AMA POLICY

Gender Disparities in Physician Income and Advancement D-200.981

Our AMA:
(1) encourages medical associations and other relevant organizations to study gender differences in income and advancement trends, by specialty, experience, work hours and other practice characteristics, and develop programs to address disparities where they exist;
(2) supports physicians in making informed decisions on work-life balance issues through the continued development of informational resources on issues such as part-time work options, job sharing, flexible scheduling, reentry, and contract negotiations;
(3) urges medical schools, hospitals, group practices and other physician employers to institute and monitor transparency of pay levels in order to identify and eliminate gender bias and promote gender equity throughout the profession;
(4) will collect and publicize information on best practices in academic medicine and non academic medicine that foster gender parity in the profession; and
(5) will provide training on leadership development, contract and salary negotiations and career advancement strategies, to combat gender disparities as a member benefit.

Citation: (BOT Rep. 19, A-08; Reaffirmed: CCB/CLRPD Rep. 4, A-13)

See also: E-9.5.5 Gender Discrimination in Medicine; Eliminating Questions Regarding Marital Status, Dependents, Plans for Marriage or Children, Sexual Orientation, Gender Identity, Age, Race, National Origin and Religion During the Residency and Fellowship Application Process H-310.919
Whereas, Some 100,000 Americans are awaiting a kidney transplant at any given time; and
Whereas, Kidney donations can be made by living donors; and
Whereas, Paying donors for organs is currently illegal; and
Whereas, Costs directly related to organ donation are paid by the recipient, but living kidney
donors still typically incur significant expenses both before and after donation – a disincentive to
donating; therefore be it
RESOLVED, That our American Medical Association seek legislation to ensure that living
kidney donors are reimbursed for expenses associated with donation of their kidney. (Directive
to Take Action)

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

Received: 05/02/18
Whereas, Differences of sex development (DSD), also known as intersex, are defined as congenital development of ambiguous genitalia (e.g., 46,XX virilizing congenital adrenal hyperplasia), congenital disjunction of sex anatomy (e.g., Complete Androgen Insensitivity Syndrome), incomplete development of sex anatomy (e.g., gonadal agenesis), sex chromosome anomalies (e.g., Turner Syndrome), and disorders of gonadal development (e.g., ovotestes); and

Whereas, Sex (the biological state of being male or female), gender (a person’s self-representation as male or female), and sexual orientation (direction(s) of erotic interest -- heterosexual, bisexual, homosexual) are three separate categories existing on a spectrum; and

Whereas, For many decades research has supported the idea that our experience of our bodies and gender identity is inherent in us and not something that can be assigned; and

Whereas, DSD is currently presented as a pathological condition requiring medical attention rather than biological variance outside of the hegemonic sex binary; and

Whereas, There is little research on the incidence of DSD, but estimates range from 1 in 5000 ambiguous genitalia to 1 in 1,500 for atypical genitalia; and

Whereas, The frequency of DSD from 1955 to 2000 was estimated to be as high as 2 percent of live births worldwide; and the frequency of individuals receiving corrective genital surgery was estimated to be 0.1-0.2 percent of all live births; and

Whereas, No straightforward recommendations exist in the U.S. for sex assignment in Neonates with DSD; however, there is a growing consensus that any surgical intervention in neonates and infants leading to irreversible changes should be done with the utmost caution; and

Whereas, The majority of reconstructive surgeries for DSD in the U.S. are typically performed during the first year; however, this timing is controversial and there is limited data on the long term psychological outcomes for patients; and

Whereas, A survey of young adults found that 93 percent of women would not have wanted their parents to agree to a genitoplasty surgery for an enlarged clitoris unless the condition were life threatening and almost all men would not have wanted sex reassignment for a micropenis if it might have impacted their sexual pleasure; and
Whereas, Medical professionals (including three former U.S. Surgeons General: Doctor Joycelyn Elders, Doctor David Satcher, and Doctor Richard Carmona) as well as national organizations such as United Nations, Amnesty International and Human Rights Watch have recommended against and are devoted to ending unnecessary surgeries on infants with DSD11,19,20,21; and

Whereas, The human rights organization Amnesty International documented numerous examples of human rights violations during instances of "invasive and irreversible 'normalizing' surgeries" for children with DSD21; and

Whereas, The 2015 European Union Report on the current legal state of affairs regarding intersex rights of member states found that at least 18 member states legally require patient (rather than parental) consent for surgical intervention in DSD22; and

Whereas, Medically unnecessary DSD surgery is defined as, "all surgical procedures that seek to alter the gonads, genitals, or internal sex organs of children with atypical sex characteristics too young to participate in the decision, when those procedures both carry a meaningful risk of harm and can be safely deferred"18; and

Whereas, The court case MC v. Aaronson, concerning the potential violation of constitutional rights of a person who underwent intersex genital mutilation without consent at age one while a ward of the state, was later dismissed by the Court of Appeals for the Fourth Circuit since there was "no fair warning to those involved in the decision regarding M.C.'s surgery that they were violating his clearly established constitutional rights;"23 and

Whereas, There are minimal studies examining the long-term impact of these surgeries, but those studies found that persons with DSD that did not have surgical intervention as infants primarily experienced psychological stress from feelings of isolation from other individuals, communities, and support groups, rather than from the absence of early surgical intervention11,24; and

Whereas, Attempting to alter a person’s sexual identity or sexual orientation through any type of therapy may cause psychological harm25; and

Whereas, Chronic juvenile stress has been associated with the development of neuropsychiatric illness in adulthood; much like the stress caused by having one’s biological sex assigned for them at birth26; and

Whereas, Permanent alterations to genitalia before a patient can consent may result in the child being assigned a gender incongruent with their gender identity and lead to adverse outcomes including loss of sensitivity, orgasmic function, and fertility2,12,27; therefore be it

RESOLVED, That our American Medical Association oppose the assignment of gender binary sex to infants with differences in sex development through surgical intervention outside of the necessity of physical functioning for an infant and believes children should have meaningful input into any gender assignment surgery. (New HOD Policy)

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

Received: 05/02/18
Whereas, The LGBTQ+ (per the Urban Dictionary – lesbian, gay, bisexual, transgender, questioning and + meaning other sexualities such as pansexual, asexual and omnisexual extra) population in the United States is estimated to be over 10 million people (4.1 percent of the population)i; and

Whereas, LGBTQ+ populations are vulnerable and often marginalized in society and in the medical systemii; and

Whereas, LGBTQ+ focus groups have established that distinguishing their identity within the medical system is often a source of great discomfortiii; and

Whereas, LGBTQ+ focus groups have also identified normalization of their gender identities as a major component of their recommendations to improve health care experiences3; and

Whereas, Intake forms in medical facilities (i.e., clinics, hospitals) often have only binary gender options, and only 5 percent of forms are gender inclusive in able to identify transgender patients4; and

Whereas, The Institute of Medicine recommends the collection of data on sexual orientation and gender identity as part of the electronic health record, but 14 percent of intake forms confuse gender and sexual orientation4,5; and

Whereas, An LGBTQ+ friendly intake form establishes a comfortable and welcoming atmosphere for the LGBTQ+ patient in the office; and

Whereas, The Gay and Lesbian Medical Association offers various guidelines for improving the care of LGBTQ+ patients, including the use of gender-neutral forms6; and

Whereas, Twenty-four percent of transgender and gender nonconforming patients reported denial of equal treatment in the while seeking healthcare7; and

Whereas, The American Medical Association has an established stance on and commitment to the ongoing improvement of nonjudgmental, nondiscriminatory, and culturally competent care of LGBTQ+ patients5; therefore be it

RESOLVED, That our American Medical Association distribute and promote the adoption of the recommendations pertaining to medical documentation and related forms in AMA policy H-315.967, “Promoting Inclusive Gender, Sex, and Sexual Orientation Options on Medical Documentation,” to our membership. (Directive to Take Action)
Fiscal Note: Not yet determined

Received: 05/02/18

RELEVANT AMA POLICY

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

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

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

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

2. Our AMA will collaborate with our partner organizations to educate physicians regarding: (i) the need for sexual and gender minority individuals to undergo regular cancer and sexually transmitted infection screenings based on anatomy due to their comparable or elevated risk for these conditions; and (ii) the need for comprehensive screening for sexually transmitted diseases in men who have sex with men; (iii) appropriate safe sex techniques to avoid the risk for sexually transmitted diseases; and (iv) that individuals who identify as a sexual and/or gender minority (lesbian, gay, bisexual, transgender, queer/questioning individuals) experience intimate partner violence, and how sexual and gender minorities present with intimate partner violence differs from their cisgender, heterosexual peers and may have unique complicating factors.

3. Our AMA will continue to work alongside our partner organizations, including GLMA, to increase physician competency on LGBTQ health issues.

4. Our AMA will continue to explore opportunities to collaborate with other organizations, focusing on issues of mutual concern in order to provide the most comprehensive and up-to-date education and information to enable the provision of high quality and culturally competent care to LGBTQ people.

Citation: CSA Rep. C, I-81; Reaffirmed: CLRDP 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;

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Whereas, The United Nations has defined human trafficking as “the recruitment, transportation, transfer, harboring or receipt of persons, by means of threat or use of force or other forms of coercion, of abduction, of fraud, or deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation. Exploitation shall include, as a minimum, the exploitation of the prostitution of others or other forms of sexual exploitation, forced labour or services, slavery or practices similar to slavery, servitude or the removal of organs;” and

Whereas, All 50 states have enacted laws criminalizing human trafficking activities; and

Whereas, AMA Board of Trustee Report 20, A-13, encourages its member groups and sections as well as the Federation of Medicine, to raise awareness about human trafficking and of resources available to help them identify and address the needs of victims; and

Whereas, The Polaris Project operates a 24-hour national human trafficking hotline which also provides assessment tools for healthcare professionals and on-line training; and

Whereas, Current AMA Policy H-65.966 will help encourage the education of physicians about human trafficking and how to report cases of suspected human trafficking to appropriate authorities to provide a conduit to resources to address the victim’s medical, legal, and social needs; and

Whereas, The January 2017 American Medical Association Journal of Ethics featured numerous perspectives on how physicians can respond for effectively to this vulnerable population and has brought awareness; and

Whereas, According to the US Department of State, Human Trafficking is the fastest growing criminal activity in the world, second only to drug trafficking. This modern-day slavery generates over $150 billion annually for organized crime; and

Whereas, Human trafficking continues to be an increasing substantial societal problem in Oklahoma and nationally; and

Whereas, Physicians are first responders in this epidemic and their education has been underwhelming compared to the rate of increase of this problem; and

Whereas, Health care providers are key stakeholders in the abolitionist movement. An estimated 28% of trafficked persons encounter the health care system while in captivity but
virtually none are ever detected. Only 1 in 100 trafficked victims are ever rescued. Recognizing red flags is absolutely essential. Without an awareness of human trafficking, victims will continue to go undetected by health care professionals; therefore be it

RESOLVED, That our American Medical Association study the effectiveness of physician education to ensure that physicians are trained to report suspected cases of human trafficking/slavery to the appropriate authorities while assuring victims have the medical, legal, and social resources they need and develop a plan of action to improve recognition of victims of human trafficking/slavery to increase the identification, referral, and rescue rate. (Directive to Take Action)

Fiscal Note: Not yet determined

Received: 05/01/18

References
- Human Trafficking Into and Within the United States: A Review of the Literature. US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.

RELEVANT AMA POLICY

Physicians Response to Victims of Human Trafficking H-65.966

1. Our AMA encourages its Member Groups and Sections, as well as the Federation of Medicine, to raise awareness about human trafficking and inform physicians about the resources available to aid them in identifying and serving victims of human trafficking.

Physicians should be aware of the definition of human trafficking and of resources available to help them identify and address the needs of victims.

The US Department of State defines human trafficking as an activity in which someone obtains or holds a person in compelled service. The term covers forced labor and forced child labor, sex trafficking, including child sex trafficking, debt bondage, and child soldiers, among other forms of enslavement. Although it’s difficult to know just how extensive the problem of human trafficking is, it’s estimated that hundreds of thousands of individuals may be trafficked every year worldwide, the majority of whom are women and/or children.

The Polaris Project -
In addition to offering services directly to victims of trafficking through offices in Washington, DC and New Jersey and advocating for state and federal policy, the Polaris Project:
- Operates a 24-hour National Human Trafficking Hotline
- Maintains the National Human Trafficking Resource Center, which provides
  a. An assessment tool for health care professionals
  b. Online training in recognizing and responding to human trafficking in a health care context
  c. Speakers and materials for in-person training
  d. Links to local resources across the country

The Rescue & Restore Campaign -
The Department of Health and Human Services is designated under the Trafficking Victims Protection Act to assist victims of trafficking. Administered through the Office of Refugee Settlement, the Department’s Rescue & Restore campaign provides tools for law enforcement personnel, social service organizations, and health care professionals.

2. Our AMA will help encourage the education of physicians about human trafficking and how to report cases of suspected human trafficking to appropriate authorities to provide a conduit to resources to address the victim’s medical, legal and social needs.

Citation: (BOT Rep. 20, A-13; Appended: Res. 313, A-15)
Whereas, The term “queer” is defined by the Human Rights Campaign (HRC) as “an umbrella term that encompasses many people as it intersects with sexual orientation and gender identity;” and “LGBTQ” has formally been adopted by the organization as a broader representation of individuals for whom its work focuses; and

Whereas, The word “queer” includes anyone who does not associate with typical classifications of gender, gender identity, and sexual orientation; rather, they have non-binary or gender expansive identities; and

Whereas, In the HRC’s 2012 survey of 50,000 self-identified LGBTQ youth age 13-18, eight (8) percent of respondents identified as a gender other than male or female; and

Whereas, According to the HRC, when asked to label their gender and sexual orientation, hundreds of respondents used “queer,” “genderqueer,” or other responses; and many others wrote in their own descriptions of more fluid identities; and

Whereas, In 2016, the AMA Board of Trustees recognized the importance of a more expansive definition of sexual and gender minorities and officially renamed the AMA Advisory Committee on LGBTQ Issues; and

Whereas, Recent AMA policies passed by the AMA House of Delegates have utilized the abbreviation “LGBTQ” and the expanded language “lesbian, gay, bisexual, transgender, and queer” (H-160.991, H-60.927); and

Whereas, The use of “LGBTQ” has come to replace “LGBT” in many aspects of culture, medicine, academics, and advocacy; and

Whereas, It is important for the AMA to recognize those within the LGBTQ population who identify as queer so that they will be fully embraced and empowered within our AMA and the healthcare community; therefore be it

RESOLVED, That our American Medical Association utilize the terminology “lesbian, gay, bisexual, transgender, and queer” and the abbreviation “LGBTQ” in all future policies and publications when broadly addressing this population, (New HOD Policy); and be it further

RESOLVED, That our AMA revise all relevant and active policies to utilize the abbreviation “LGBTQ” in place of the abbreviations “LGBT” and “GLBT” where such text appears (Modify Current HOD Policy); and be it further
RESOLVED, That our AMA revise all relevant and active policies to utilize the terms “lesbian, gay, bisexual, transgender, and queer” to replace “lesbian, gay, bisexual, and transgender” where such text appears. (Modify Current HOD Policy)

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

Received: 05/10/18

References:
Human Rights Campaign Post-election Survey of Youth www.hrc.org/youth
https://assets2.hrc.org/files/assets/resources/HRC_PostElectionSurveyofYouth.pdf?_ga=2.1866225.1552857023.1523827449-11965525142.1505150368

RELEVANT AMA POLICY

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 Disparities Among Gay, Lesbian, Bisexual and Transgender Families D-65.995
Our AMA supports reducing the health disparities suffered because of unequal treatment of minor children and same sex parents in same sex households by supporting equality in laws affecting health care of members in same sex partner households and their dependent children.
Citation: (Res. 445, A-05; Modified: CSAPH Rep. 1, A-15)

Health Care Needs of Lesbian, Gay, Bisexual and Transgender 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, quee/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, quee/questioning individuals) experience intimate partner violence, and how sexual and gender minorities present with intimate partner violence differs from their cisgender, heterosexual peers and may have unique complicating factors.
3. Our AMA will continue to work alongside our partner organizations, including GLMA, to increase physician competency on LGBTQ health issues.
4. Our AMA will continue to explore opportunities to collaborate with other organizations, focusing on issues of mutual concern in order to provide the most comprehensive and up-to-date education and information to enable the provision of high quality and culturally competent care to LGBTQ people.
Citation: CSA Rep. C, I-81; Reaffirmed: CLRPD Rep. F, I-91; CSA Rep. 8 - I-94; Appended: Res. 506, A-00; Modified and Reaffirmed: Res. 501, A-07; Modified: CSAPH Rep. 9, A-08; Reaffirmation A-12; Modified: Res. 08, A-16; Modified: Res. 903, I-17; Modified: Res. 904, I-17

Whereas, The Mission Statement of our AMA for many years has been to “Promote the art and science of medicine and the betterment of public health”; and

Whereas, Our AMA has been spending an increasing amount of time discussing physician suicide, burn out and general malaise with practicing medicine; and

Whereas, Darwin has taught that survival depends on adaptation; and

Whereas, It is vital for its survival that our AMA adapt to changing times by updating its Mission Statement; therefore be it

RESOLVED, That our American Medical Association consider its current mission statement to read: The AMA promotes professionalism, the art and science of medicine, physician wellness and the betterment of public health. (Directive to Take Action)

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

Received: 05/10/18