

Policy Compendium on Confidential Health Services for Adolescents

2nd Edition

Editors: Madlyn C. Morreale Amy J. Stinnett Emily C. Dowling

In collaboration with members of the American Medical Association (AMA) National Coalition on Adolescent Health and the AMA Educational Forum on Adolescent Health

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Information contained in this compendium was verified as of November 2004. Policies issued or modified subsequently are not included. All policies in this compendium have been included with the explicit permission of the organizations that issued them. Permissions were obtained between November 2004 and September 2005. Detailed permission information for each policy is included in the References on pages 83 – 89.

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Availability

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This document builds on the outstanding work, *Policy Compendium on Confidential Health Services for Adolescents*, originally edited by Janet E. Gans [Epner] and published in 1993 by the American Medical Association. The Center for Adolescent Health & the Law sincerely appreciates the willingness of the AMA to collaborate with us to update this important document. We particularly wish to recognize the numerous contributions made by Missy Fleming and Kelly J. Towey of the AMA's Child and Adolescent Health Program.

We also wish to acknowledge the cooperation of numerous individuals who represent the organizations that are included in this compendium. Their willingness to provide materials and review the contents for accuracy is greatly appreciated. Their names are provided in Appendix A.

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This second edition of *Policy Compendium on Confidential Health Services for Adolescents* represents a collaborative effort between the Center for Adolescent Health & the Law, the American Medical Association (AMA), and members of the AMA National Coalition on Adolescent Health and the AMA Educational Forum on Adolescent Health.

The first edition of this Compendium was published in 1993 by the American Medical Association and contained policies that were current as of August 1, 1992. Recognizing that the original edition has played a critical role in educating both health care providers and policy makers about the need for confidential health services for adolescents, the Center for Adolescent Health & the Law and the AMA sought to revise the Compendium to reflect the organizational policies that have been adopted during the past decade and to present those in the context of the current legal, policy, and health care environment.

The Center for Adolescent Health & the Law is a national nonprofit organization that supports laws and policies that promote the health of adolescents and their access to comprehensive health care. The American Medical Association created the AMA National Coalition on Adolescent Health in 1987 and, in 2002, convened a complementary group, the AMA Educational Forum on Adolescent Health. Together, the AMA Coalition and Forum include more than 25 organizations whose members provide direct health care services to adolescents.

During 2002 and 2003, the Center for Adolescent Health & the Law contacted the national health care provider organizations that participate in the AMA National Coalition on Adolescent Health or the AMA Educational Forum on Adolescent Health to solicit their input to this Compendium. The following organizations provided documents that are cited in this Compendium:

American Academy of Child & Adolescent Psychiatry (AACAP)
American Academy of Family Physicians (AAFP)
American Academy of Pediatric Dentistry (AAPD)
American Academy of Pediatrics (AAP)
American College of Emergency Physicians (ACEP)
American College Health Association (ACHA)
American College of Obstetricians and Gynecologists (ACOG)
American College of Physicians (ACP)
American College of Preventive Medicine (ACPM)
American Medical Association (AMA)
American Nurses Association (ANA)
American Psychiatric Association (APA)
American Psychological Association (APA)
American Public Health Association (APHA)
American School Health Association (ASHA)
National Assembly on School-Based Health Care (NASBHC)
National Association of Pediatric Nurse Practitioners (NAPNAP)
National Association of School Psychologists (NASP)
National Association of Social Workers (NASW)
Society for Adolescent Medicine (SAM)
se organizational policy can be reflected in a variety of formally-endorsed documents, the data sources for this endium include a number of materials, including:
position statements;
resolutions;
position or policy papers;
comments submitted in response to proposed regulations (particularly related to the HIPAA medical privacy regulations):

testimony or letters submitted to Congress or the Administration;
codes or principles of ethics; and
other formal organizational practice guidelines.

In some cases, these documents are available in published journals or on the organizations' websites. To ensure that the data collection process yielded both comprehensive and accurate results, individuals representing the organizations included in this Compendium were asked to review the draft, provide copies of any relevant policies that had not been identified in the preliminary data collection phase, and confirm that the policies quoted herein reflect the current policies of their organization.

These formal policy documents were analyzed to identify a range of themes such as the rationale for supporting confidential health care for the general population and for adolescents in particular; policies and procedures to protect confidentiality; the roles of parents and guardians in adolescent health care; the importance of informing adolescents and parents about confidentiality protections and limitations to those protections; policies about informed consent and confidentiality for specific health services; confidentiality concerns for particular populations of adolescents; and statements about confidentiality in particular health care settings. The text and tables of this Compendium have been organized according to these themes.

The text for this Compendium has been taken verbatim from the organizations' policy documents. At times, punctuation has been edited or citation numbers from the original text have been deleted to improve readability. Within each section of this Compendium, policy statements are presented in alphabetical order by organization. Where applicable, policy statements that have been endorsed by more than one organization are presented at the beginning of the section. When text from a particular statement is applicable to more than one section, it has been repeated.

While this Compendium represents a broad range of policies with respect to confidential health services for adolescents, its scope is, nonetheless, limited. For example, this Compendium does not address policies related to genetic testing, health education or sexuality education provided outside of context of confidential health care delivery, adolescents' participation in research, or the myriad ethical and legal requirements for confidentiality and reporting of child abuse.

As with the original document, this second edition of *Policy Compendium on Confidential Health Services for Adolescents* is intended for a diverse group of professionals who work with or on behalf of adolescents. Its goals are:

- 1) To educate health care professionals and policy makers about the essential role that confidential services play in adolescents' access to health care;
- 2) To encourage organizations to develop or clarify policy recommendations about confidentiality which address the unique developmental and health care needs of adolescents and to educate their membership about their policies; and
- To serve as a resource for individuals and organizations working to ensure that public policy supports adolescents' access to confidential health services.

Importance of Confidentiality for Adolescents ^a

For the past several decades, public policy, laws, and professional guidelines have recognized that some adolescents would forego or delay seeking needed health care if they could not receive confidential care and that this result would lead to negative health outcomes both for individual adolescents and the health of the public in general. ^{b, c} This recognition is well grounded in what research findings have told us about the importance of confidentiality to adolescents.

Research studies spanning more than 30 years have provided insight into the extent to which confidentiality is important to adolescents and the reasons why that is true. Findings from the 1970s and early 1980s have been confirmed in more recent studies. Collectively, these findings demonstrate that adolescents' privacy concerns affect their access to and use of many different types of health services. Particular concerns are related to sexual activity, pregnancy, sexually transmitted infections (STIs), HIV, substance abuse, and mental health.

Evidence gained from research confirms that concerns about privacy can act as a significant barrier to adolescents seeking health care. ^{d, e, f, g, h, i, j} This has been documented in both large nationally representative surveys and smaller state or local studies. In one national survey, 35 percent of middle and high school students who reported that they did not seek health care they needed cited one of their reasons as "not wanting to tell their parents." ^e

The impact of privacy concerns on whether adolescents seek care for specific sensitive health concerns appears to be even higher. In a recent survey in one state, 59 percent of single, sexually active girls under age 18 who were using family planning clinics indicated they would stop using *all* sexual health services, discontinue use of *specific* sexual health services, or delay testing or treatment for HIV or other STIs, if their parents were informed that they were seeking prescribed contraceptives. § Moreover, in a subsample of this study, of the adolescent girls who indicated they would stop using family planning services if their parents were informed of their use of contraceptive services, only one percent reported that they also would stop having sexual intercourse; instead, the vast majority reported that they would continue to have sex, but use less effective contraceptive methods or none at all. §

Recent research also has confirmed that privacy concerns influence adolescents' choice of health care provider or site, h, k the degree to which they communicate openly with health care providers, l and their willingness to accept services such as pelvic examinations and testing for STIs or HIV. m, n, o

Ultimately, when adolescents are discouraged from seeking health care due to concerns that the care will not be confidential, the result can lead to adverse health outcomes. Further research is needed on the magnitude of this effect, but at least two recent studies have measured the potential increase in pregnancies and STIs, with the likelihood of significant increases in public financial costs, when this occurs. P, q

The Legal Framework for Confidentiality in Adolescent Health Care

The legal framework for consent and confidentiality in adolescent health care includes both state and federal laws. These laws are embodied in constitutional doctrine, statutes enacted by legislatures, regulations promulgated by administrative agencies, and cases decided by courts. Statutes known as "state minor consent laws" are particularly notable for their role in determining the consent requirements for adolescents to receive health care. ^r At the federal level, the new federal medical privacy regulations known as the "HIPAA Privacy Rule" are of similar importance for the confidentiality of adolescents' health information. ^{c, s} Many other laws have great significance in specific circumstances as well, such as statutes providing for the emancipation of minors, court decisions delineating the mature minor doctrine, regulations protecting adolescents' confidentiality in family planning and substance abuse programs, and court decisions interpreting the constitutional right of privacy.

Many of the laws that protect the confidentiality of health care information apply to adolescents who are minors as well as to adults. ^t They include the constitutional right of privacy, minor consent laws, medical records and health privacy laws, evidentiary privileges, and funding statutes, among others. Most significant for this Compendium are

the state minor consent laws, the HIPAA Privacy Rule, and provisions affecting the federal Title X Family Planning Program and federal drug and alcohol treatment programs.

Confidentiality & Disclosure Provisions of Minor Consent Laws

In almost every state, the minor consent laws contain one or more provision that addresses the confidentiality or the disclosure of information when a minor may give consent for care. In a few states, either the minor consent laws or the medical privacy laws specify that when a minor has consented to care, information about the care may not be disclosed without the permission of the minor. ^r (State-specific information about state minor consent laws may be found in English and Kenney, 2003. ^r)

In some states, a general disclosure provision applies to all of the minor consent laws; in others, a specific disclosure provision is included within one or more but not all of the minor consent laws. ^r Thus the disclosure provisions are not necessarily consistent among different services even within one state. Most of the disclosure provisions that are included address the circumstances in which a health care provider may disclose information to a parent when a minor has consented to the care. These disclosure provisions are of particular importance in light of the HIPAA Privacy Rule.

The HIPAA Privacy Rule

The most important recent development affecting the confidentiality of adolescents' health care information is embodied in federal medical privacy regulations, the HIPAA Privacy Rule, issued under the Health Insurance Portability and Accountability Act of 1996. The rule creates new rights for individuals to have access to their protected health information and to control the disclosure of that information in some circumstances. It contains specific requirements that affect medical records and information pertaining to the care of minors. ^u

The HIPAA Privacy Rule provides that, in general, when minors legally consent to health care or can receive it without parental consent, or when a parent has assented to an agreement of confidentiality between the minor and the health care provider, the parent does not necessarily have the right to access the minor's health information. Whether the parent may do so is dependant upon "state or other applicable law."

Thus, a health care provider must look to state laws or other laws to determine whether they specifically address the confidentiality of a minor's health information in relation to parents' access to information. The relevant sources of state or other law that a health care provider must consider include state minor consent laws, state medical privacy laws, the federal confidentiality rules for the federal Title X Family Planning Program, the federal confidentiality rules for drug or alcohol programs, and court cases interpreting both these laws and the constitutional right of privacy.

Under HIPAA, state or other laws that explicitly require, permit, or prohibit disclosure of information to a parent are controlling. If state or other laws are silent on the question of parents' access to a minor's health information, a health care professional exercising professional judgment has discretion to determine whether or not to grant access. The deference to professional judgment in the HIPAA Privacy Rule, when state and other laws are silent on the question of parents' access to information, underscores the importance of the confidentiality policies contained in this Compendium.

Taken separately and together, these policy statements can provide important guidance and support to health care professionals when they are called upon to make discretionary determinations about whether to disclose confidential information about adolescents. These policy statements also can provide support for health care professionals who are working within their own institutions and health care sites to develop appropriate guidelines to help in making these determinations.

Special Considerations for Family Planning, Contraception, & Pregnancy Related Care

Special considerations pertain to consent and confidentiality questions related to family planning, contraception, and pregnancy related care for minors. Most importantly, these include court decisions based on the constitutional right

of privacy and the confidentiality requirements that are part of the federal Title X Family Planning Program and Medicaid. $^{v,\,w}$

The U.S. Supreme Court has held that the constitutional right of privacy extends to minors as well as adults and that it encompasses minors' reproductive decisions. x, y The Supreme Court also has explicitly recognized that minors' access to contraceptives falls within the realm protected by the constitutional right of privacy. y Moreover, courts have not found that parental involvement for minors to obtain contraceptives is required and have struck down statutes that attempted to require parental consent or notification for contraceptives in several cases. z, aa

In every state, at sites that receive funds under the federal Title X Family Planning Program, minors are legally able to obtain family planning services and contraceptive care without parental consent or notification. ^v Title X specifies that family planning services must be available without regard to age and includes detailed confidentiality rules. Title X encourages, but does not require, family participation. The Medicaid program also requires that confidential family planning services be available to adolescents as well as adults who are eligible for Medicaid. ^w

Special Considerations for Drug and Alcohol Care

A set of detailed federal confidentiality regulations is applicable to facilities that meet a definition of federal drug or alcohol treatment programs. ^{bb} These rules do not contain provisions that determine whether or not a minor may consent to services in the programs. However, they do provide that if a minor is allowed to consent to services under state law, specific confidentiality protections from the federal rules apply. Almost every state allows minors to give their own consent for drug or alcohol care. ^r In some states, the minor consent laws also contain confidentiality or disclosure provisions. Special care must be taken to understand the relationship between these laws and the federal drug and alcohol confidentiality rules.

Ethical Framework for Confidentiality in Adolescent Health Care

In addition to the legal underpinnings, there is a strong ethical foundation for providing confidentiality protections in adolescent health care. ^{cc} Protecting the confidentiality of adolescents' health information is a professional duty that derives from the moral tradition of physicians and the goals of medicine and that is well established as a duty for most health care professionals. Ethical principles of autonomy, nonmaleficence, beneficence, and justice are all key elements of the ethical framework for confidentiality in adolescent health care. Many of the organizations whose policies are represented in this Compendium have adopted ethical codes, ethical principles, or ethics manuals. These often embody the ethical bases for providing adolescents with confidentiality protection.

Confidentiality Challenges in Clinical Settings and Financing Systems

Many practical issues affect a clinician's ability to provide confidential care for adolescents. Clinicians must determine minors' capacity to give informed consent. They need to understand and screen for situations that will limit their ability to provide minors with confidential care, such as suspected physical or sexual abuse and risk of homicide or suicide. Clinicians also face challenges concerning how to maintain their records when the parent has rights to obtain some—but not all—of their adolescents' health information. Electronic medical records, over which physicians may have little control, add further complexity to this issue. c

Third party reimbursement creates additional challenges. Many adolescents are covered either by public or private insurance, but some are unwilling or unable to use their insurance coverage for contraceptive services, diagnosis and treatment of STIs, or other sensitive issues, because they worry that their parents will be notified through the billing and insurance claims process, despite the fact that minor consent laws may permit them to seek these services without parental consent. The legal rules for integrating confidential care for adolescents with a complex system of third party reimbursement is still very much in evolution. Effective implementation of confidentiality protections for adolescents in the third party payer arena will require the willing and active cooperation of both health care providers and third party payers. ^c

Finally, clinicians face the challenge of conveying the protections and limitations of confidentiality to adolescent patients and their parents. They also face the challenge of encouraging communication between adolescent patients and their parents in a way that is respectful of adolescent's need for privacy and the support that parents can provide. ^c

Ensuring access to confidential health care for adolescents involves significant challenges from the perspectives of clinical decision making and counseling, information systems, and reimbursement mechanisms. The policies contained in this Compendium provide significant guidance on many of these issues.

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- a. This introduction was written by Abigail English, JD, Director, Center for Adolescent Health & the Law. Brief portions of this introduction originally appeared in English A, Kenney, KE. State Minor Consent Laws: A Summary, 2nd Edition. Chapel Hill, NC: Center for Adolescent Health & the Law, 2003 and in English A, Ford CA. The HIPAA Privacy Rule and adolescents: Legal questions and clinical challenges. Perspectives on Sexual and Reproductive Health 2004;36:80-86 and are used here with permission.
- b. Ford CA and English A. Limiting confidentiality of adolescent health services: What are the risks? JAMA 2002;288(6):752-753.
- c. English A, Ford CA. The HIPAA Privacy Rule and adolescents: Legal questions and clinical challenges. Perspectives on Sexual and Reproductive Health 2004;36:80-86.
- d. Klein J, McNulty L, Flatau C. Teenager's self-reported use of services and perceived access to confidential care. Arch Pediatr Adolesc Med 1998;152:676-682.
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- n. Ford CA, Best DB, Miller WC. Confidentiality and adolescents' willingness to consent to STD testing. Arch Pediatr Adolesc Med 2001;155:1072-73.
- o. Meehan TM, Hansen H, Klein WC. The impact of parental consent on the HIV testing of minors. AJPH 1997;97:1338-1341.
- p. Franzini, L, Marks, E, Cromwell, PF et al. Economic costs due to health consequences of teens' loss of confidentiality in obtaining reproductive health care services in Texas. Arch Pediatr Adolesc Med 2004;158:1140-1146.
- q. Zavodny M. Fertility and parental consent for minors to receive contraceptives. AJPH 2004;94:1347-1351.

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- r. English A, Kenney, KE. State Minor Consent Laws: A Summary, 2nd Edition. Chapel Hill, NC: Center for Adolescent Health & the Law, 2003.
- s. Standards for Privacy of Individually Identifiable Health Information, 45 C.F.R. Parts 160 and 164. Final Rule, 65 Federal Register 82461 (Dec. 28, 2000); Final Rule, 67 Federal Register 53182 (Aug. 14, 2002).
- t. The term "minor" refers to an individual who has not reached the age of "majority" or adulthood as defined by state law. In most states, the age of majority is 18. (See reference r.)
- u. Appendix C of this Compendium provides additional background information about the significance of the HIPAA Privacy Rule for adolescents.
- v. 42 U.S.C. §§ 300 et seq. 42 C.F.R. Part 59.
- w. 42 U.S.C. §§ 1396a(a)(7), 1396d(a)(4)(C). 42 C.F.R. § 441.20.
- x. Planned Parenthood of Central Missouri v. Danforth, 428 U.S. 52 (1979).
- y. Carey v. Population Services International, 531 U.S. 678 (1977).
- z. T.H. v. Jones, 425 F. Supp. 873 (D. Utah), aff'd in part 425 U.S. 986 (1976).
- aa. Planned Parenthood Federation of New York v. Heckler, 712 F. 2d 650 (D.C. Cir. 1983); National Family Planning and Reproductive Health Association v. Department of Health and Human Services, F. 2d 650 (D.C. Cir. 1983.
- bb. 42 C.F.R. §§ 2.11 et seq.
- cc. Society for Adolescent Medicine. Confidential health care for adolescents: Position paper of the Society for Adolescent Medicine. J Adolesc Health 2004;35:160-167.

Policy Statements About the Importance of Confidentiality

This Compendium includes nearly 100 policy statements that affirm the critical role that confidentiality plays in ensuring timely access to essential health care services. Reflecting the significant interest that this topic has generated in recent years, more than 80 percent of the 95 documents cited here were published or revised within the past decade. The majority of items cited in this Compendium are formally-endorsed resolutions or policy/position statements that have been published in professional journals and/or on the organizations' websites. In addition, 11 organizations have adopted formal codes of ethics, ethical principles, or ethics manuals that address confidentiality, and those are cited here.

Each of the 20 national health care provider organizations cited in this Compendium has adopted or endorsed at least one policy statement affirming the critical role that confidentiality plays in ensuring access to essential health services. The American Academy of Pediatrics (AAP), the American Medical Association (AMA), and the Society for Adolescent Medicine (SAM) have endorsed the greatest numbers of policy statements cited in this Compendium, with 22, 12, and nine respectively. Because a significant number of the organizations in this Compendium provide more specialized services (such as mental health or reproductive health) or services in particular health settings (such as schools or emergency departments), it is particularly interesting to note that 15 of the 20 organizations have endorsed at least three statements that are included in this Compendium.

As illustrated in Table 1, among the organizations cited herein, the rationale for providing confidential access to health services for the adolescent population differs little from that offered to support confidential access for the general population (which may include adolescents). Thirteen organizations discuss the protection of patient confidentiality as a fundamental component of ethical practice and 11 organizations discuss the role that confidentiality plays in establishing open, honest communication between patients and health care providers.

Nine organizations identify confidentiality as playing a critical role in patients' decisions to seek health care on a timely basis and to remain in care once they have begun treatment. Eight organizations discuss the role that confidential communication plays in helping health care professionals offer the best possible care to their patients. Moreover, several organizations discuss the importance of confidentiality for promoting adolescents' autonomy and helping adolescent patients learn to take responsibility for their own health care.

Table 1: Policy Statements About the Importance of Confidentiality a, b

	Refer to the (correspondi	ns with Policies that General Population ing page numbers in impendium) c	Refer to A	vith Policies that dolescents page numbers in pendium)
☐ Protecting patient confidentiality is a fundamental component of ethical professional practice.	AAFP (33) ACEP (35) ACHA (35) ACOG (35) ACP (36)	AMA (33) ANA (38-39) APA1 (33, 40) APA2 (40-41) NASW (42-43)	AACAP (33, 46-47) AAFP (44) AAP (44) ACOG (44) NASP (54-55, 78-79)	
☐ Confidentiality and privacy are essential to establishing trust and open, timely, and honest communication between patients and health care providers.	AAFP (33) ACEP (35) ACHA (35) ACOG (35)	ACP (36) AMA (37-38) APA1 (40)	AACAP (73) AAFP (48) AAP (75) ACOG (50-52)	ACPM (64) SAM (55-58)
☐ Confidential communication between health care providers and patients is essential to the effectiveness of treatment and/or providing high quality/the best possible care.	AAFP (33) ACP (36) AMA (38) ANA (39)	APA1 (40)	AAFP (44-46) AAP (44-46) ACOG (44-46) SAM (44-46, 55-58)	
☐ Confidentiality protections increase the likelihood that patients will seek care on a timely basis and/or remain in care.	ACHA (35) ACP (36) APA1 (40)		AACAP (73) AAFP (44-46) AAP (44-46, 61- 62)	ACOG (44-46, 70) ACPM (64) SAM (44-46, 55, 61)
☐ Assurances of confidentiality promote the dignity and/or autonomy of the patient.	ACEP (35) ACHA (35)	AMA (38)	SAM (55)	
☐ Learning to make appropriate health care decisions is an important developmental task. As adolescents mature, they should assume responsibility for their personal health and medical decisions.			AAP (49) ACOG (50-52) AMA (52-53)	
☐ Adolescents tend to underutilize health care services. Concerns about confidentiality represent a significant barrier to care for adolescents.			AAFP (44-46) AAP (44-46) ACOG (44-46, 50-52)
☐ Patient confidentiality is essential for preventing discrimination.	ACP (36) ACPM (37)		AACAP (73)	

^a See page ii for the key to abbreviations of the names of the organizations cited in this table. Because the American Psychiatric Association and the American Psychological Association are each abbreviated as APA, they are listed here as APA1 and APA2, respectively.

^b The statements in this table are intended to provide a general thesis of the organizations' policy statements. Please refer to the page numbers indicated in the table for the precise language adopted by each organization and for appropriate citations to the source material.

 $^{^{\}mathrm{c}}$ The positions cited in this column refer to the general patient population, which may or may not include adolescents.

Policy Statements Regarding Disclosure of Confidential Information and the Scope and Limitations of Confidentiality Protections

While each of the 20 organizations has endorsed the critical importance of confidentiality in access to health services, their policy statements also reflect considerable agreement that a patient's right to confidentiality is not unconditional. As illustrated in Table 2, 15 organizations have adopted policy statements that address the scope and limitations of confidentiality protections and situations where disclosure of confidential information may be required. In general, the policy statements emphasize the importance of having the patient provide consent or authorization before confidential information is disclosed, with two important exceptions: when disclosure is required by law (13 organizations); and when the health care professional is concerned that the patient is in a lifethreatening situation and is likely to harm himself/herself or others (13 organizations).

Ten organizations recommend that health care providers and patients should explicitly discuss the meaning, scope, and limits of confidentiality and circumstances in which health information will be disclosed. Of these ten, seven make this recommendation particularly with respect to communication with adolescent patients, and three organizations (ACOG, AMA, and SAM) also recommend that health care providers have these discussions with the parents or guardians of their adolescent patients.

Seven organizations have endorsed policy statements that emphasize that the rights, safety, and welfare and medical interests of the patient should be the primary considerations for health care professionals when making judgments about the disposition of confidential information. Table 2 also includes summaries of several policy statements which discuss the importance of ensuring that when information is disclosed, it should only be to individuals or entities who have a legitimate right to receive it, and that such disclosures should be time-limited and restricted to include only the information that is necessary to achieve the purpose for which disclosure was authorized.

Table 2: Policy Statements Regarding Disclosure of Confidential Information and the Scope and Limitations of Confidentiality Protections ^{d, e}

	Refer to the Ge (corresponding	with Policies that eneral Population g page numbers in appendium) ^f	Organizations with to Adole (corresponding p this Compe	escents page numbers in
 Patient confidentiality and privacy should be protected unless: Consent or authorization for disclosure has been provided by the patient (or the patient's legally authorized representative. 	AAFP (33-34) ACEP (35) ACHA (35) ACP (36-37) ACPM (37) AMA (37)	ANA (33, 39-40) APA1 (33, 40) APA2 (33, 40- 41) NASW (33, 42-43)	AACAP (33) AAP (49) AMA (52-53)	
Disclosure is required by law (court order or statute).	AAFP (33-34) ACEP (35) ACHA (35) ACOG (35-36) ACP (36-37) AMA (33, 37-38)	ANA (33, 38-39) APA1 (33, 40) APA2 (33, 40- 41) NASW (33) ^h	AACAP (33) AAP (49, 75) AMA (52-53) SAM (55-58)	
■ The health care provider is concerned that the patient is in a life-threatening situation and will harm himself/herself or others.	AAFP (33-34) ACEP (35) ACP (36-37) AMA (37-38) ANA (38-40)	APA1 (40) APA2 (40-41)	AACAP (46-47, 73- 74) AAFP (44-46, 48) AAP (44-46, 50, 62, 74-75) ACOG (44-46, 50-52)	AMA (52-53, 65) NASP (54-55, 78- 79) NASW (79) SAM (44-46, 55)
☐ Confidential health information should not be disclosed without the consent of the child or the child's parent or guardian except in those situations in which failure to release information would result in clear danger to the child or others.			NASP (54-55, 78-79)	
☐ Specific confidences of the patient and the parents or guardians should be protected unless this course would involve untenable risks or betrayal of care-taking responsibilities. The release of information regarding an adolescent to persons outside the family requires the agreement of parents or guardians.			AACAP (46-47)	
☐ Health care providers and patients should (routinely) discuss (or patients should receive written information regarding) the meaning, scope, and limits of confidentiality, how confidential information will be used and circumstances in which health information will be disclosed.	ANA (39-40) APA2 (40-41) NASW (42-43)		AACAP (46-47) AAFP (44, 48) AAP (44) ACOG (44, 50-52, 70) AMA (53) NASP (54-55, 78-79)	SAM (55-58, 61)

d See page ii for the key to abbreviations of the names of the organizations cited in this table. Because the American Psychiatric Association and the American Psychological Association are each abbreviated as APA, they are listed here as APA1 and APA2, respectively.

^e The statements in this table are intended to provide a general thesis of the organizations' policy statements. Please refer to the page numbers indicated in the table for the precise language adopted by each organization and for appropriate citations to the source material.

f The positions cited in this column refer to the general patient population, which may or may not include adolescents.

g The policies cited in this column refer to the general adolescent population. See Tables 5 and 6 for additional policy statements about disclosure of confidential information and the scope and limitations of confidentiality for special populations of adolescents and for specific health services delivered to adolescents.

h See page 42 for the provision in NASW's Code of Ethics that obligates a social worker to request that a court withdraw or limit an order requiring disclosure of confidential information without a client's consent and such disclosure could cause harm to the client.

Table 2: Policy Statements Regarding Disclosure of Confidential Information and the Scope and Limitations of Confidentiality Protections (cont'd)

	Organizations with Policies that Refer to the General Population (corresponding page numbers in this Compendium)	Organizations with Policies that Refer to Adolescents (corresponding page numbers in this Compendium)
☐ Health care providers should explain the meaning, scope, and limitation of confidentiality protections to the parents and guardians of their adolescent patients.		ACOG (50-52, 70) AMA (53) SAM (55,61)
☐ The rights, well-being, safety, and/or best medical interest of the individual patient should be the primary factors in arriving at any professional judgment concerning the disposition of confidential information.	ANA (38-39)	AAFP (48)
Health care providers should recognize the responsibility to their patients first and foremost.	AAFP (33) AMA (33) APA1 (33)	AACAP (33)
The welfare of the patient should be the basis of all medical judgments.	ACOG (35-36)	
The principal concerns of child and adolescent psychiatrists are the welfare and optimum development of the child and adolescent patient(s) being served.		AACAP (46-47)
☐ Before breaching a patient's confidentiality, health care providers should inform/discuss the reasons for the disclosure with the patient.	ACP (36-37) NASW (42-43)	AACAP (46-47) AMA (52-53)
☐ If breaching confidentiality is necessary, it should be done in a way that minimizes harm to the patient.	ACP (36)	
☐ Patients should be informed of any significant infringement on their privacy of which they may otherwise be unaware.	AMA (38)	
☐ Disclosure of confidential information should be time limited and/or restricted to only the information necessary for the purposes for which the disclosure is made.	AAFP (33-34) APA1 (33) ACPM (37) APA2 (33, 40-41) AMA (37) NASW (33, 42-43) ANA (33, 38-40)	
☐ If it is known that the results of a particular test or other information must be given to governmental authorities or other third parties, this should be explained to the patient as part of the process of obtaining informed consent.	ACOG (35)	
☐ Confidential information may be shared with another health care provider who is directly involved in the patient's care or is being consulted regarding treatment of the patient.	AAFP (33-34) ANA (38-39) APA2 (40-41)	
☐ Confidential information should only be disclosed to other entities that have a legitimate right to the information and can ensure that confidentiality will be protected.	ANA (33) APA1 (33) APA2 (33)	

Policy Statements Regarding Institutional Policies and Procedures to Safeguard Confidentiality

Two-thirds of the organizations (13 of 20) included in this Compendium have endorsed policy statements that address the need for institutional policies and procedures to safeguard confidentiality. See Table 3. Eight of these have endorsed statements regarding the need for health care providers (and institutions, in some cases) to ensure that written and electronic medical records are maintained, stored, reproduced, transferred, and disposed in a manner that protects confidentiality. Six organizations discuss the need for health care providers and institutions to establish policies and procedures to ensure that patient confidentiality is protected and six organizations describe specific administrative aspects of health care delivery, such as billing and quality improvement activities, where patient confidentiality should be protected.

In Table 3, differences between policy statements that refer to the general population versus those referring to adolescents begin to emerge. Specifically, six organizations (AACAP, AAP, ACOG, AMA, NASP, and SAM) have endorsed statements about institutional policies and procedures that address unique issues for adolescents and their families. These include, for example, policies recommending that health care providers and staff receive training and on-going education about laws and regulations regarding consent and confidentiality for adolescents and about their own institutional policies and procedures regarding confidentiality. In addition, three organizations (ACOG, AMA, and SAM) recommend that minor patients be referred to other health care providers or sites if health care providers are unable to provide or protect confidential access to health services for adolescents for a variety of reasons, such as the inability to implement reimbursement or billing procedures that protect adolescents' confidentiality.

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Table 3: Policy Statements Regarding Institutional Policies and Procedures to Safeguard Confidentiality $^{\rm i,\ j,\ k}$

	Organizations with Policies that Refer to the General Population (corresponding page numbers in this Compendium) ¹	Organizations with Policies that Refer to Adolescents (corresponding page numbers in this Compendium)
☐ Health care providers (and institutions) should establish policies and procedures to ensure that patient confidentiality is protected.	ACP (36-37) ACPM (37) ANA (38-39)	AAP (50) ACOG (50-52, 63-64, 70) SAM (55-58)
☐ Health care providers (and institutions) should ensure that written and electronic medical records are maintained, stored, reproduced, transferred, and/or disposed in a manner that protects confidentiality.	AAFP (33-34) NASW (33, 42-43) ACPM (37) ANA (33) APA1 (33) APA2 (33, 40-41)	AAP (50) NASP (78-79)
☐ Health care providers (and institutions) should develop office protocols for staff, patients, and parents regarding when confidentiality must be waived, when information may be disclosed, guidelines for reimbursement, access to medical records, and/or appointment scheduling.		AAP (50) ACOG (50-52) SAM (55, 61)
☐ Health care providers (and staff) should be trained regarding institutional policies and procedures related to confidentiality.		AAP (50) ACOG (50-52) SAM (55)
☐ Health care providers should receive education and ongoing training to ensure they know and understand state and federal laws and regulations regarding consent and confidentiality for adolescents.		AMA (53) SAM (55-58)
☐ Institutional policies should require health care providers whose views on confidentiality restrict the provision of services to a minor to refer the patient to another practitioner.		ACOG (63-64)
☐ Health care providers who are unable to provide or protect confidential access to health services for adolescents should/may refer those patients to other providers/sites where confidential services are available.		AMA (52-53) SAM (55-58)
☐ Confidentiality should not be compromised by economic considerations. When costs or billing procedures compromise an adolescent's ability to obtain confidential care, payment alternatives or referral of the patient to other health care providers/sites should be offered.		ACOG (52) SAM (55)
☐ Co-payments should not be imposed for services that adolescents are reluctant to seek without assurances of confidentiality.		SAM (55)

ⁱ See page ii for the key to abbreviations of the names of the organizations cited in this table. Because the American Psychiatric Association and the American Psychological Association are each abbreviated as APA, they are listed here as APA1 and APA2, respectively.

^j The statements in this table are intended to provide a general thesis of the organizations' policy statements. Please refer to the page numbers indicated in the table for the precise language adopted by each organization and for appropriate citations to the source material.

k See Table 7 for additional statements about policies and procedures for particular health settings.

¹ The positions cited in this column refer to the general patient population, which may or may not include adolescents.

Policy Statements About the Roles of Parents and Guardians in Adolescent Health Care

Nine organizations have endorsed policy statements about the roles of parents and guardians in adolescents' general health care. ^m Most commonly, these organizations state that health care providers should encourage their adolescent patients to inform and involve their parents or other trusted adults in their general health care decisions. Several organizations expand on this theme by advocating for health care providers to work to facilitate family communication for a variety of reasons, such as to enhance parents' confidence in their roles and to help parents support the developmental goal of encouraging adolescents to assume increasing personal responsibility in their own health care.

Four organizations (AAFP, AAP, ACOG, and SAM) have endorsed policy statements explaining that most adolescents voluntarily communicate with their parents about their health concerns and that this communication is not something that can or should be imposed by law, but rather is a function of the inherent quality of the relationships between adolescents and parents. Nonetheless, these organizations state, even adolescents in the best of family and household environments may, at times, be unwilling to communicate with their parents. In these circumstances, mandatory parental involvement, consent, and/or notification laws reduce the likelihood that some adolescents will seek essential health care services. Similarly, the American Medical Association has endorsed a policy statement which says that when parental involvement is not in the best interest of the adolescent or may prevent the adolescent from seeking care, confidentiality must be assured.

Five organizations (AAFP, AAP, ACOG, AMA, and SAM) recommend that health care providers should provide adolescents with the opportunity for private examination and counseling, separate from their parents or guardians. Four organizations (AAFP, AAP, ACOG, and SAM) agree that the same confidentiality should be preserved between the adolescent patient and the provider as between the parent and the provider, and two organizations (ACOG and AMA) have endorsed statements which recognize that both adolescents and parents have privileged relationships with the health care provider.

m See Tables 5-7 for additional policy statements regarding the role of health care providers in encouraging communication between special populations of adolescents and their parents, and with respect to specific services or care delivered in particular settings.

Table 4: Policy Statements About the Roles of Parents and Guardians in Adolescent Health Care n, o, p, q, r

	(corresponding p	ith Relevant Policies page numbers in this pendium)
☐ Health care services should be provided in the context of the family (and the community).	AAP (49) NAPNAP (54)	NASW (55)
☐ Parents and adolescents each have a private and privileged relationship with the health care provider.	ACOG (50-52) AMA (53)	
☐ The same confidentiality will be preserved between the adolescent patient and the provider as between the parent/adult and the provider.	AAFP (44) AAP (44)	ACOG (44) AMA (53)
☐ While parental support is important, this support should be balanced with confidentiality and respect for the adolescent's autonomy in health care decisions and in relationships with health care providers.	ACP (52)	
☐ Working with families in health care decision-making and information sharing should take into account the adolescent's maturity, capacity for independent decision-making, and right to privacy and confidentiality.	AAP (49) SAM (55)	
☐ Adolescent patients should be encouraged to inform and involve their parents (or other trusted adults) in their health care decisions. Health care providers should facilitate this communication as appropriate.	AAFP (44, 48, 61) AAP (44, 49, 62) ACOG (44, 50-52, 61, 63-64, 70)	AMA (52-53) NASP (54-55, 78-79) SAM (44-46, 55-58, 61, 72)
☐ Health care providers should seek to strengthen family communication skills and family involvement in adolescent decisions by enhancing parental skills for listening, communicating, valuing, and nurturing throughout the childhood years.	AAP (62-63)	
☐ Health care providers should stress to parents that they share a common goal – the health and well-being of the adolescent patient. The mutual trust that follows this common goal will enhance and support the adolescent-health care provider relationship.	ACOG (50-52)	
☐ Providing confidential care does not preclude working toward the goal of family communication. Adolescents often voluntarily share information with their parents after they consult privately with their health care provider.	AAFP (44-46) AAP (44-46) ACOG (44-46)	SAM (44-46, 55)
☐ Family-centered practitioners understand that health care experiences can enhance parents' confidence in their roles and, over time, increase the competence of adolescents to take responsibility for their own care.	AAP (49-50)	
☐ Health care providers should educate parents to encourage their adolescents to assume increasing personal responsibility in health care	AAFP (48) ACOG (50-52)	

 $^{^{\}rm n}$ See page ii for the key abbreviations of the names of the organizations cited in this table.

^o The statements in this table are intended to provide a general thesis of the organizations' policy statements. Please refer to the page numbers indicated in the table for the precise language adopted by each organization and for appropriate citations to the source material.

P See Table 1 for additional policy statements regarding the importance of confidentiality in the patient-provider relationship and the importance of confidentiality in promoting patient autonomy and responsibility in health care decisions.

q See Tables 5, 6, and 7 for additional policy statements regarding the roles of parents and guardians for special populations of adolescents, access to specific health services, and services delivered in particular health care settings.

^r See Table 8 for additional policy statements regarding relevant laws and regulations about confidential care for adolescents.

Table 4: Policy Statements About the Roles of Parents and Guardians in Adolescent Health Care (cont'd)

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
☐ Most adolescents voluntarily communicate with their parents about health concerns. This is not predicated by laws, but by the quality of their relationships. Adolescents who live in warm, loving, caring environments, who feel supported by their parents, will in most instances communicate with their parents about an urgent health concern. However, even adolescents in the best of household environments may, at times, be unwilling to communicate with their parents because they do not want to disappoint or hurt their parents.	AAFP (44-46) AAP (44-46) ACOG (44-46) SAM (44-46)
☐ For minors who are mature enough to be unaccompanied by their parents for their examination, confidentiality of information disclosed during an exam, interview, or in counseling should be maintained.	AMA (52-53)
☐ Health care providers should facilitate communication with parents regarding appointments and payments for services in a manner supportive of the adolescent's rights to confidentiality.	AAFP (44, 48) AMA (53) AAP (44) ACOG (44)
☐ Mandatory parental involvement, consent, and/or notification reduce the likelihood that some adolescents will seek health care.	AAFP (44-46) ACOG (44-46) AAP (44-46) SAM (44-46)
☐ Where the law does not require otherwise, health care providers should permit a competent minor to consent to medical care and should not notify parents without the patient's consent. In cases where the health care provider believes that without parental involvement and guidance, the minor will face a serious health threat, and there is reason to believe the parents will be helpful and understanding, disclosure to the parents is ethically justified. When parental involvement is not in the best interest of the adolescent or when parental involvement may prevent the adolescent from seeking care, confidentiality must be assured.	AMA (52-53)

Policy Statements About Confidentiality Concerns for Special Populations of Adolescents

As illustrated in Table 5, eight organizations recognize in their formally-endorsed policy statements that some populations of adolescents have particular concerns regarding confidentiality. For example, the Society for Adolescent Medicine describes the unique issues facing adolescents who have run away, are homeless, or are living on the street. This population of particularly vulnerable young people may face administrative barriers to receiving health care when unaccompanied by their parents. They may mistrust adults (including health care providers) and be concerned that seeking health services may result in notification to the police or other authorities.

Four organizations (AACAP, AAP, ANA, and SAM) have endorsed policy statements discussing the confidentiality concerns of adolescents in state custody, including the child welfare system, the juvenile justice system, and the public mental health system. These statements primarily focus on issues related to confidential access to mental health and substance abuse services and to HIV-antibody testing and care.

The American Academy of Family Physicians and the National Association of Pediatric Nurse Practitioners have endorsed policy statements regarding the importance of confidentiality to adolescents who are gay, lesbian, bisexual, or transgender. Their statements emphasize the particular importance of protecting confidentiality for these adolescents because information about their sexual orientation or identity may expose them to prejudice, discrimination, hostility, harassment, violence, and/or abandonment by their families.

Table 5 also includes numerous policy statements from five organizations (AAFP, AAP, AMA, APHA, and SAM) that describe the particular needs of pregnant and parenting adolescents with respect to confidentiality. These statements discuss a range of health care services that should be available to pregnant and parenting adolescents on a confidential basis, such as contraceptive services, pregnancy testing, prenatal and postpartum care, delivery services, and abortion. Several organizations endorse the statement that health care providers should encourage pregnant adolescents to discuss their pregnancy with their parents or other trusted adults and to seek advice and support from these individuals. Nevertheless, as illustrated in Table 5, there is general agreement among these organizations that while voluntary communication between pregnant adolescents and their parents is beneficial for many young people, requiring such communication through parental consent and parental notification laws will discourage many adolescents from seeking timely access to professional care and advice.

Table 5: Policy Statements About Confidentiality Concerns for Special Populations of Adolescents $^{\rm s,\ t}$

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
Adolescents who have Run Away, are Homeless, or are Living on the Street	
☐ Concern about confidentiality represents a key barrier to receiving necessary health care services for adolescents who have run away, are homeless, or are living on the streets. Many of these youth have been victimized by adults and are reluctant to trust health care professionals. Legal concerns may lead to fear of police or social service agency notification.	SAM (59)
Adolescents in State Custody	
☐ Within the limits of HIPAA, information regarding mental health and substance abuse services should be shared among organizations and agencies providing services to adolescents in the child welfare system and their families. This information should follow the adolescent from placement to placement.	AACAP (59) AAP (59)
Adolescents in foster care have a right to family participation in all aspects of planning, service delivery, and evaluation. Family for these youth may include biological, foster, and adoptive parents, grandparents and their partners, as well as kinship care givers and others who have primary responsibility for providing love, guidance, food, shelter, clothing, supervision, and protection.	AACAP (59) AAP (59)
□ Voluntary, confidential HIV testing with pre and post counseling, informed consent, and follow up care should be available to adolescents in juvenile detention or correctional facilities, foster care, and the mental health system. The privacy of these young people should be protected to the maximum extent possible.	SAM (60)
□ Voluntary, confidential HIV testing with pre and post counseling should be available upon request to individuals in federal, state, juvenile, and local detention or correctional facilities. Those with clinical indication of HIV disease and those who have engaged in risk behaviors should be encouraged to test for HIV. HIV testing should be conducted with informed consent for the purposes of initiating treatment.	ANA (59-60, 71)
☐ Large scale screening of detained and incarcerated individuals may not be efficacious. Mandatory testing is not warranted.	ANA (59-60, 71)
☐ Confidentiality is particularly important for inmates because being labeled as HIV positive may place them at undue risk for compromised safety.	ANA (59-60, 71)
☐ Staff in jails, prisons, and juvenile confinement facilities should receive training on confidentiality as it relates to HIV. Staff should remain informed about confidentiality laws.	ANA (59-60, 71)
Adolescents who are Gay, Lesbian, Bisexual, or Transgender	
☐ Protection of confidentiality is needed to appropriately address issues related to sexual orientations.	AAFP (48)

 $^{^{\}rm S}$ See page ii for the key abbreviations of the names of the organizations cited in this table.

^t The statements in this table are intended to provide a general thesis of the organizations' policy statements. Please refer to the page numbers indicated in the table for the precise language adopted by each organization and for appropriate citations to the source material.

Table 5: Policy Statements About Confidentiality Concerns for Special Populations of Adolescents (cont'd)

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
Adolescents who are Gay, Lesbian, Bisexual, or Transgender (cont'd)	
□ Confidentiality is particularly important for gay, lesbian, (bisexual and transgender) youth because information about their sexual orientation may expose them to prejudice, discrimination, hostility, harassment, violence, and/or abandonment. Health care providers may be failing to fully address issues of sexual orientation and confidentiality with adolescents. In order to advocate for GLBT youth, health care providers should maintain confidentiality regarding sexual orientation in accordance with state regulations.	NAPNAP (60)
Pregnant and Parenting Adolescents u, v	
☐ Protection of confidentiality is needed to appropriately address issues related to unintended pregnancy.	AAFP (48)
☐ Pregnant adolescents should have affordable, confidential access to contraceptive services, prenatal and postpartum care, and safe and legal abortion services	APHA (60, 65-66)
Adolescents should be strongly encouraged to involve their parents or other trusted adults in decisions regarding pregnancy termination, and the majority of them voluntarily do so. A minor's decision to involve parents is determined by the quality of the family relationship, not by laws. Family communication is inherently a family responsibility, and parents themselves create the emotional atmosphere that fosters productive dialog.	AAP (62-63)
☐ If parental support or involvement is not possible, pregnant adolescents should be encouraged to seek the advice of other trusted adults.	AAP (62-63) APHA (65-66) AMA (65)
□ Health care providers should strongly encourage minors to discuss their pregnancy with their parents. They should ensure that a minor's reluctance to talk with her parents is not based on misperceptions about the likely consequences of parental involvement. Health care providers should not feel or be compelled to require minors to involve their parents before deciding whether to undergo an abortion. The adolescent patient should be allowed to decide if parental involvement is appropriate. Health care providers should explain under what circumstances (e.g., life-threatening emergency) the minor's confidentiality will be abrogated and should ensure the minor has made an informed decision.	AMA (65)
☐ Health care providers should convey the results of a pregnancy test to the adolescent alone in a private setting. In considering confidentiality, the health care provider should assess the adolescent's ability to understand the diagnosis of pregnancy and appreciate the implications of that diagnosis. The diagnosis should not be conveyed to others, including parents, until the patient's consent has been obtained, except when there are concerns about suicide, homicide, or abuse.	AAP (62)
☐ When an adolescent requests pregnancy-related care, including pregnancy testing, prenatal and postnatal care, and delivery services, health care providers should recognize that parental involvement may be counterproductive to the health of the patient.	AMA (52-53)

^u See Table 6 for additional policy statements regarding confidential access to contraception, pregnancy-related services, abortion, and other reproductive health services.

^v See Table 8 for additional statements regarding relevant laws and regulations about confidential care for adolescents.

Table 5: Policy Statements About Confidentiality Concerns for Special Populations of Adolescents (cont'd)

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
Pregnant and Parenting Adolescents (cont'd)	
□ While parental involvement in minors' pregnancy-related decisions may be very helpful, it can also be punitive, coercive and/or abusive. Parental involvement laws, whether notification or consent, for adolescent reproductive health care do not appreciably discourage adolescent sexual activity and provide a strong disincentive for many adolescents against seeking professional care or advice. Efforts to compel, rather than encourage parental notification of teenagers' abortions serve only to delay and deter access of pregnant teens to abortion services and violate their constitutional right of privacy	APHA (65-66)
☐ The decision to terminate a pregnancy should rest with the pregnant adolescent in concert with the advice and counsel of her physician. Although involvement of significant others should be strongly encouraged, particularly for minors, mandatory parental consent and/or notification should not be required.	SAM (68)

Policy Statements About Adolescents' Confidential Access to Specific Health Care Services

Nearly three-quarters of the organizations (14 of 20) cited in this Compendium have endorsed policy statements about ensuring adolescents' confidential access to specific health services such as: preventive health services; dental services; contraception, pregnancy-related services, abortion, and other reproductive health services; services related to HIV and other sexually-transmitted infections (STIs); and mental health and substance abuse care. See Table 6. As would be expected, a number of these policy statements were endorsed by organizations that provide specific services, such as dental care (the American Academy of Pediatric Dentistry), mental health and substance abuse services (American Academy of Child and Adolescent Psychiatry, American Psychiatric Association, and National Association of School Psychologists), and services related to sexual and reproductive health care and STIs (American College of Obstetricians and Gynecologists).

Nevertheless, Table 6 illustrates that many organizations support adolescents' confidential access to a wide range of specific health care services. For example, seven organizations (AAFP, AAP, ACOG, ACP, ACPM, APHA, and SAM) have endorsed the importance of confidentiality in delivery of reproductive health-related services, such as sexuality education in the clinic setting, contraceptive services and counseling, pregnancy testing, prenatal and postpartum care, and abortion counseling and services. Several of these statements reinforce the value of encouraging adolescents to involve their parents in their reproductive health care, but recognize that requiring parental involvement may be counterproductive to the patient's health.

Seven organizations (AACAP, AAP, ACP, ACPM, AMA, NASP, and SAM) have endorsed statements regarding adolescents' confidential access to education, counseling, testing, diagnosis, and treatment of HIV and other STIs. As with other sexual and reproductive health services, many of these organizations encourage voluntary, not mandatory involvement of parents and other trusted adults in HIV- and STI-related care. Four organizations (AACAP, AAP, NASP, and SAM) have endorsed statements reflecting a particular concern about adolescents' confidential access to HIV-antibody testing, the importance of explaining any limits that may exist regarding the confidentiality of test results, and policies related to disclosure of results to other health care professionals or staff providing services to the adolescent.

As illustrated in Table 2, eight organizations have endorsed policy statements about the necessity of breaching confidentiality when an adolescent is in a life-threatening situation or is perceived to be at risk to himself/herself or to others. While these statements are not focused on adolescents' access to mental health services specifically, they do address the responsibility of health care providers to recognize significant mental health needs of their adolescent patients. Table 6 includes a wide range of policy statements that address the importance of adolescents' access to confidential mental health and substance abuse services. Four of these organizations have endorsed at least one policy statement that discusses the importance of ensuring that adolescents are given the opportunity to provide informed consent for drug and alcohol testing, except in very limited situations such as when an adolescent patient does not have the capacity to provide informed consent or the patient is at risk for serious harm that could only be averted if the specific drug were identified. In addition, the American Academy of Pediatrics opposes mass drug testing programs for students particularly when the results of these screening programs may serve as a prerequisite for participation in school activities. Similarly, the American College Health Association recommends that drug testing programs for collegiate student athletes must ensure that informed consent is provided, that the results remain confidential, and that participants are offered due process protections in the event of sanctions for alleged violations.

Table 6: Policy Statements About Adolescents' Confidential Access to Specific Health Care Services $^{\rm w,\ x}$

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
Preventive Health Services	
$\hfill \square$ Preventive health services should be provided to a dolescents on a confidential basis.	SAM (61)
Dental Services	
☐ Issues of consent and confidentiality should be addressed in the provision of dental care of adolescent patients.	AAPD (61)
Contraception, Pregnancy-Related Services, Abortion, and Other Reproductive Health Services $^{\rm y,\ z}$	
☐ Concern about confidentiality is one of the primary reasons that adolescents hesitate or delay obtaining family planning or contraceptive services.	AAFP (44-46) APHA (65-66) AAP (44-46, 61) SAM (44-46) ACOG (44-46)
☐ Health care providers should integrate specific, culturally-sensitive, and non-judgmental sexuality education and counseling into the confidential relationships they develop with children, adolescents, and families to complement the education they obtain at school and at home. This education should respect and acknowledge the individual patient's and family's issues and values.	AAP (62)
☐ Health care providers should encourage voluntary communication between adolescent patients and their parents/family regarding sexual behavior and reproductive health. Health care providers should explain the benefits of parental involvement to their adolescent patients.	AAFP (61) AMA (65) AAP (61) APHA (65-68) ACOG (61, 63-64) SAM (61) ACP (64)
☐ The potential health risks to adolescents if they are unable to obtain reproductive health services are so compelling that legal barriers and deference to parental involvement should not stand in the way of needed health care for patients who request confidentiality.	AAFP (61) SAM (61) AAP (61) ACOG (61) APHA (65-68)
☐ While parental involvement in minors' decisions may be very helpful, it can also be punitive, coercive, and/or abusive. Parental involvement laws, whether notification or advice, for adolescent reproductive health do not appreciably discourage sexual activity and provide a strong disincentive for seeking professional reproductive health care services.	APHA (65-66)
☐ When an immature minor requests contraceptive services or pregnancy-related care (including pregnancy testing, prenatal and postnatal care, and delivery services), physicians must recognize that requiring parental involvement may be counterproductive to the health of the patient. Health care providers should encourage parental involvement, however if the minor continues to object, his or her wishes ordinarily should be respected.	AMA (52-53)
☐ If a minor patient requests advice about contraception or termination of a pregnancy without a parent's knowledge, the health care provider may wish to attempt to persuade the patient of the benefits of having parents involved, but information should not be provided to others without the patient's permission. In these cases, health care providers should be guided by their conscience in light of the law.	ACP (64)

w See page ii for the key to abbreviations of the manes of the organizations cited in this table. Because the American Psychiatric Association and the American Psychological Association are each abbreviated as APA, they are listed here as APA1 and APA2, respectively.

^x The statements in this table are intended to provide a general thesis of the organizations' policy statements. Please refer to the page numbers indicated in the table for the precise language adopted by each organization and for appropriate citations to the source material.

^y See Table 5 for additional policy statements regarding services for pregnant adolescents.

^z See Table 8 for additional policy statements regarding relevant laws and regulations about confidential care for adolescents.

Table 6: Policy Statements About Adolescents' Confidential Access to Specific Health Care Services (cont'd)

	(corresponding	with Relevant Policies page numbers in this apendium)
Contraception, Pregnancy-Related Services, Abortion, and Other Reproductive Health Services (cont'd)		
☐ Comprehensive reproductive health services should be provided on a confidential basis to all adolescents enrolled in the State Children's Health Insurance Program (SCHIP).	ACPM (64)	
☐ Comprehensive health care for adolescents should include a sexual health history with assurances of confidentiality.	AAP (61)	
☐ Adolescents should have access to confidential contraceptive services and counseling.	AAFP (61) ACPM (64)	APHA (65-68) SAM (68)
☐ Protection of confidentiality is needed to appropriately address unintended pregnancy.	AAFP (48)	
☐ Adolescents should have access to confidential pregnancy testing.	AAP (62) ACPM (64)	SAM (68)
☐ Adolescents should have access to confidential prenatal and postpartum care.	ACPM (64) APHA (65-66)	SAM (68)
☐ Adolescents should have access to confidential abortion counseling and services.	AAP (62-63) ACPM (64)	APHA (65-66) SAM (68)
Services Related to HIV and Other Sexually Transmitted Infections aa, bb		
☐ Sexually active adolescents who refuse STI testing because of privacy concerns place themselves at risk of complications from undiagnosed infections and also limit the potential for screening programs to reduce STI rates.	ACPM (70)	
☐ Adolescents should have access to education, counseling, and health care services for the prevention, screening, diagnosis, and treatment of STIs based on their own consent.	AMA (70) SAM (68)	
☐ When an immature minor requests treatment for STIs, physicians must recognize that requiring parental involvement may be counterproductive to the health of the patient. Health care providers should encourage parental involvement, however if the minor continues to object, his or her wishes ordinarily should be respected.	AMA (52-53)	
☐ If a minor patient requests advice about treatment of an STI without a parent's knowledge, the health care provider may wish to attempt to persuade the patient to involve his/her parent, but information should not be provided to others without the patient's permission. In these cases, health care providers should be guided by their conscience in light of the law.	ACP (64)	
☐ Health care providers should encourage adolescents to seek the support and involvement of their parents (or other trusted adults) in their HIV-related care whenever possible.	AAP (69-70) SAM (72)	

 $^{^{\}mathrm{aa}}$ See Table 5 for additional policy statements regarding services for adolescents in state custody.

bb See Table 8 for additional policy statements regarding relevant laws and regulations about confidential care for adolescents.

Table 6: Policy Statements About Adolescents' Confidential Access to Specific Health Care Services (cont'd)

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
Services Related to HIV and Other Sexually Transmitted Infections (cont'd)	
□ Although it is usually best to involve the family in the health care of adolescents, this is not always the case. Deference to parents' wishes to be informed must not interfere with needed evaluation or treatment of HIV disease in adolescents. For adolescents who are able to understand the implications of testing and treatment and are capable of informed consent, and in the absence of laws to the contrary, it is best to proceed on the basis of this consent alone rather than insisting on parental involvement.	AAP (69-70)
☐ HIV antibody testing must be done with the adolescent's informed consent.	AACAP (68-69) SAM (72) AAP (69-70)
☐ Health care providers should explain the limits of confidentiality to adolescent patients regarding HIV testing and test results.	AAP (69-70)
□ Confidential and anonymous HIV antibody testing should be available to adolescents. There should be no mandatory HIV antibody testing of individual adolescents or population groups as a pre-requisite for admission to programs, services, or placements. There should be no involuntary HIV-antibody testing of adolescents.	SAM (72)
Health care providers should inform adolescent patients of their HIV status in order to help them make appropriate decisions about sexual behavior, treatment, and participation in clinical trials.	AAP (70)
☐ Results of adolescent patients' HIV antibody tests should be maintained in a confidential manner.	AACAP (68-69) SAM (72)
An adolescent's consent should be obtained before release of any information regarding his/her HIV status. Disclosure of an adolescent's HIV status should be held to the same legal and ethical standards as disclosure of the HIV status of adult patients.	AAP (69-70)
☐ HIV-related information about an adolescent should be shared among health care professionals and other service providers only with appropriate authorization.	SAM (72)
An adolescent patient's HIV status should be shared only with staff members who need to know that information in order to provide appropriate health care to the patient.	AACAP (68-69)
☐ Disclosure of HIV status to school authorities without an adolescent's consent generally is not indicated.	AAP (69-70)
☐ Classroom teachers and school psychologists should not have access to information about an adolescent's HIV status unless it can be documented that such disclosure would benefit the adolescent and consent for disclosure has been provided.	NASP (71-72)
Mental Health and Substance Abuse Services cc, dd	
☐ Protection of confidentiality is needed to appropriately address issues of depression, suicide, substance abuse, and domestic violence.	AAFP (48)

cc See Table 5 for additional policy statements regarding services for adolescents in state custody and Table 7 for additional policy statements about school-based mental health

 $^{^{\}rm dd}~{\rm See}~{\rm Table}~8~{\rm for}~{\rm additional}~{\rm policy}~{\rm statements}~{\rm regarding}~{\rm relevant}~{\rm laws}~{\rm and}~{\rm regulations}~{\rm about}~{\rm confidential}~{\rm care}~{\rm for}~{\rm adolescents}.$

Table 6: Policy Statements About Adolescents' Confidential Access to Specific Health Care Services (cont'd)

	(corresponding pa	h Relevant Policies age numbers in this endium)
Mental Health and Substance Abuse Services (cont'd)		
☐ Confidentiality should be breached when an adolescent is in a life-threatening situation or is a risk to himself/herself or to others. Health care providers should inform the appropriate person when they believe an adolescent is at risk of suicide.	AACAP (46-47, 73) AAFP (44-46, 48) AAP (44-46, 50, 62, 75) ACOG (44-46, 50-52)	AMA (52-53, 65) NASP (54-55, 78-79) NASW (79) SAM (44-46, 55)
☐ Careful judgment must be exercised by the psychiatrist in order to include, where appropriate, the parents or guardian in the treatment of a minor. At the same time, the psychiatrist must assure the minor proper confidentiality.	APA1 (54)	
☐ When an immature minor requests treatment for drug and alcohol abuse or mental illness, physicians must recognize that requiring parental involvement may be counterproductive to the health of the patient. Health care providers should encourage parental involvement, however if the minor continues to object, his or her wishes ordinarily should be respected.	AMA (52-53)	
☐ Concern about confidentiality is one of the primary reasons that adolescents hesitate or delay obtaining treatment for substance abuse.	AAFP (44-46) AAP (44-46)	ACOG (44-46) SAM (44-46)
☐ Confidentiality plays a central role in creating an atmosphere of mutual trust and comfort which is essential to obtaining a comprehensive substance abuse history.	AAP (74)	
☐ Adolescents should be given the right to informed consent for drug and alcohol testing.	AACAP (73) AAP (74)	
☐ If confidentiality concerns are addressed, a competent adolescent may consent to testing and counseling for substance use without the knowledge of parents, police, or school administrators.	AAP (75)	
□ Involuntary drug testing is not appropriate for adolescents with decisional capacity, even with parental consent, and should be done only if there are strong medical or legal reasons to do so. Patient consent for drug or alcohol testing may be waived when the patient's mental status or judgment is impaired. Involuntary testing for substance abuse would only be justified if the adolescent lacks decisional capacity or is at risk for serious harm that could be averted only if the specific drug were identified. If the treatment and therapy would not be changed by testing, involuntary testing would not be justified.	AAP (74)	
When an adolescent patient is dangerous to himself/herself, is unable to make a positive treatment alliance, does not show concern about his/her condition, and or refuses help, informed consent for an alcohol or drug test may be obtained from the parent alone.	AACAP (73)	
☐ Because serious legal consequences may result from a positive drug screen, health care providers should have a candid discussion with adolescent patients regarding confidentiality of test results.	AAP (74)	
"Voluntary screening" is a term applied to many mass, non-suspicion-based drug screening programs, yet such programs may not be truly voluntary as there are often negative consequences for those who choose not to take part. Participation in mass screening programs for substance use should not be a pre-requisite for participation in school activities.	AAP (74)	

Table 6: Policy Statements About Adolescents' Confidential Access to Specific Health Care Services (cont'd)

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
Mental Health and Substance Abuse Services (cont'd)	
A drug testing program for collegiate student athletes should provide for informed consent by all students required to participate and due process protections should be available in the event of sanctions for alleged violations. Test results should be handled in a strictly confidential manner, in accordance with established university procedures. Test results should be included in medical or counseling records only, not in athletic or academic records.	ACHA (75)
☐ Screening or testing for drug or alcohol use is improper under any circumstances if clinicians cannot be reasonably certain that the laboratory results are valid and that patient confidentiality is assured.	AAP (74)
☐ Health care providers should be knowledgeable about procedures to protect the confidentiality of drug and alcohol test results.	AACAP (73-74)

Policy Statements About Confidentiality for Adolescents Served in Particular Health Care Settings

Slightly more than half of the organizations included in this Compendium (11 of 20) have endorsed policy statements regarding adolescents' access to confidential health care in particular settings. As illustrated in Table 7, these organizations were most likely to discuss adolescents' confidentiality in the context of health care delivered in school settings. These policy statements discuss a variety of subjects with respect to school-based health care, such as the importance of having appropriate policies and procedures in place before services are delivered and discussing issues of confidentiality with parents and adolescents during the school registration process or as early as possible once services are sought.

Several organizations discuss the importance of encouraging parents to be involved in their students' health education and supervision whenever possible and the need to implement policies, implementing procedures to protect the confidentiality of a student's health information, and clarifying when information about a student may be shared with the student's primary health care provider, other school health professionals (e.g., nurses), and/or outside agencies.

Table 7 also includes summaries of several policy statements regarding services delivered to adolescents in college health settings, emergency departments, and managed care settings. The American College Health Association's policy statement contains many relevant provisions, including the importance of protecting confidentiality of patient health records, ensuring that confidential information is not available or disclosed to other students or staff who are not directly involved in the patients' care or qualified to provide care, and providing students and staff with information about policies related to the rights and responsibilities associated with patients' confidential access to health services.

Similarly, the American Academy of Pediatrics, the American College of Emergency Physicians, and several other health care provider organizations whose policy statements do not appear in this Compendium have endorsed a comprehensive, joint policy statement which addresses the unique issues associated with delivering confidential health services in emergency department settings. This policy statement includes, for example, the explicit recommendation that while health care providers should seek consent from the patient or family as soon as possible when emergency care is needed, appropriate medical care for minors with an urgent or emergent condition should never be delayed or withheld because consent could not be obtained. In addition, AAP and ACEP recommend that every clinic, office practice, and emergency department should develop written policies and guidelines on billing, parental notification, and confidentiality for unaccompanied minors.

One organization, the Society for Adolescent Medicine, has endorsed a policy statement which recommends that managed care organizations should incorporate protections for adolescents to receive confidential care and should implement procedures to allow adolescents to give informed consent for their own health care, as allowed by state and federal law.

Table 7: Policy Statements About Confidentiality for Adolescents Served in Particular Health Care Settings $^{\rm ee,\,ff}$

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
School Health Services ^{gg}	
☐ When health services are provided in school settings, patient confidentiality should be protected.	AACAP (76) NASP (54-55, 78-79)
☐ School health personnel should disclose confidential information if there is a danger to the student or another individual.	NASP (54-55, 78-79) NASW (79)
☐ Policies about confidentiality should be established with advice of expert legal advisors and school officials before patient services are offered.	AMA (76)
☐ Parents should be encouraged to be involved in their student's health education and supervision whenever appropriate and possible.	AAP (76) NASBHC (77) AMA (53) NASP (54-55, 78-79)
☐ With parental involvement and appropriate consent, children and adolescents should receive comprehensive primary care, including social services, mental health and health education, with a focus on wellness.	NAPNAP (54)
☐ School health centers should have a policy regarding parental consent.	NASBHC (77)
☐ Issues of confidentiality should be identified and discussed during the registration process. If the school's plan includes provisions for adolescents to receive services without parental notification or health plan billing, this should be addressed at the time of registration.	AAP (76)
☐ Written consent should be obtained from the parent and, when appropriate, from the student before the student health information is shared with the student's primary care provider, other school health professionals (nurse, counselor), and/or outside agencies.	AAP (76) ASHA (76-77)
☐ All school personnel should regard as confidential all information related to a student's physical, mental and developmental status.	ASHA (76-77)
☐ School health assessments should provide for each child to be examined individually (rather than in groups) to protect confidentiality.	AAP (76)
☐ School policies and practices for medication administration must ensure that student confidentiality is protected.	AAP (76)
☐ Parents and students should be fully informed in advance about all relevant aspects of school psychological services. School psychologists should discuss limits of confidentiality at the onset of the professional relationship.	NASP (54-55, 78-79)
☐ School psychologists should discuss the rights of parents and students regarding the creation, modification, storage, and disposal of confidential materials that will result from the provision of school psychological services.	NASP (54-55, 78-79)
☐ School psychologists discuss confidential information only for professional purposes and only with persons who have a legitimate need to know.	NASP (54-55, 78-79)
☐ Collaboration between health care providers in school-based health centers and school nurses enhances students' health and academic outcomes. This collaboration should include joint policies and procedures that ensure students' confidentiality and continuity and coordination of care.	NASBHC (77)

ee See page ii for the key to abbreviations of the names of the organizations cited in this table.

ff The statements in this table are intended to provide a general thesis of the organizations' policy statements. Please refer to the page numbers indicated in the table for the precise language adopted by each organization and for appropriate citations to the source material.

gg See Table 8 for additional policy statements regarding laws and regulations about confidential care for adolescents.

Table 7: Policy Statements About Confidentiality for Adolescents Served in Particular Health Care Settings (cont'd)

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
School Health Services (cont'd)	
□ Schools have a responsibility to ensure that students' health information is maintained, stored, retrieved, transferred, and destroyed in ways that protect the students' and families' privacy.	ASHA (76-77) NASP (78-79)
□ Student health information should be distinguished from other types of school records. School health records should have the same protections granted other medical records by federal and state law.	ASHA (76-77)
□ School personnel should ensure confidentiality of health information whether transmitted through conversation, billing activity, telemedicine, or the release of medical records.	NASBHC (77)
Regular, periodic training should be provided to staff, contracted service providers, and others concerning school district policies and procedures to ensure confidentiality.	ASHA (76-77)
College Health Services	
□ Student health records and information are confidential. Students have the authority to approve or refuse their release in accordance with applicable federal and state laws.	ACHA (79)
A student's confidential health information should not be available or disclosed to other health care providers who are not directly involved in the student's care or to other students working at the health service that are not trained or qualified to provide care.	ACHA (79)
□ College health programs should maintain a health record system that protects patient confidentiality as information is collected, processed, maintained, stored, retrieved, and distributed.	ACHA (79)
☐ Students and staff should be provided with information about policies related to the rights and responsibilities of patients and treatment of unemancipated minors.	ACHA (79)
Emergency Departments hh	
☐ Health care providers should seek consent from the patient or family as soon as possible when emergency care is needed, but appropriate medical care for minors with an urgent or emergent condition should never be withheld or delayed because of problems with obtaining consent.	AAP (79-81) ACEP (79-81)
☐ Emergency health care professionals should discuss confidentiality concerns with minor patients and should seek assent from the patient, as appropriate for his or her developmental age and understanding, for parental involvement, but should honor the patient's wishes for confidentiality.	AAP (79-81) ACEP (79-81)
☐ Emergency health care professionals should document in the patient's medical record all discussions of assent or consent, including the identity of the person providing permission for treatment, an assessment of the patient's maturity and understanding, and efforts to obtain consent from the parent or legal guardian.	AAP (79-81) ACEP (79-81)
☐ If treatment is given to unaccompanied minors without prior parental consent, parents should be advised of the treatment rendered as soon as possible.	ACEP (81)

 $^{^{\}mathrm{hh}}$ See Table 8 for additional policy statements regarding relevant laws and regulations about confidential care for adolescents.

Table 7: Policy Statements About Confidentiality for Adolescents Served in Particular Health Care Settings (cont'd)

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
Emergency Departments (cont'd)	
☐ Every clinic, office practice, and ED should develop written policies and guidelines on billing, parental notification, and confidentiality for unaccompanied minors.	AAP (79-81) ACEP (79-81)
☐ Financial reimbursement should not limit a minor's access to emergency medical care or result in a breach of patient confidentiality, particularly if an unintended parental notification may result from the receipt of an itemized medical bill.	AAP (79-81) ACEP (79-81)
Managed Care Settings	
Managed care arrangements should incorporate protections for adolescents to receive confidential care and procedures allowing adolescents to give informed consent for their own health care, as allowed by state and federal law.	SAM (82)

Policy Statements About Federal, State, and Local Laws that Protect Adolescents' Access to Confidential Health Services

Half of the organizations cited in this Compendium (10 of 20) have endorsed policy statements which refer to federal, state, and local laws that protect adolescents' access to confidential health care. Most commonly, these statements recommend that health care providers and plans should understand relevant laws and policies regarding confidentiality for adolescents (9 organizations). Some of these statements refer to laws and policies about a specific health service (e.g., substance abuse treatment) and others refer to the need for health care providers in particular health care settings (e.g., schools) to be informed about relevant confidentiality laws. Three organizations (AAFP, AAP, and ACOG) also recommend that adolescents and parents should understand relevant laws and regulations governing confidentiality for minors.

As illustrated in Table 8, several organizations have endorsed policy statements which state that while parental involvement in adolescent health care is desirable, mandatory parental consent or notification should not be legislated. Finally, six organizations (AAFP, AAP, ACOG, AMA, APHA, and SAM) have endorsed policy statements recommending that health care providers should advocate for public policies that ensure and protect adolescents' confidential access to health care, such as by opposing efforts to repeal minor consent laws and efforts to undermine confidentiality protections for adolescents and by working proactively to support public policies that guarantee adolescents' access to essential health services.

Table 8: Policy Statements About Federal, State, and Local Laws that Protect Adolescents' Access to Confidential Health Services $^{\rm ii,\ jj}$

☐ Health care providers (and plans) should understand relevant laws and regulations about confidentiality for adolescents.	Organizations with Relevant Policies (corresponding page numbers in this Compendium)	
	AAFP (44, 48) AAP (44, 50) ACOG (44, 50-52, 70)	AMA (53) NASP (54-55, 78-79) SAM (55-58)
Health care providers should understand legislative and regulatory requirements that address the secure transmission, storage, and public accessibility of patient medical information.	AAP (50) NASP (54-55, 78-79)	
 Health care providers should be familiar with state and local laws regarding confidential reproductive health care for adolescents. 	AAP (62) AMA (65)	APA1 (71)
Health care providers should understand local and state laws regarding testing and treatment for HIV and STIs.	AACAP (68-69) AAP (69-70) ACOG (70)	ANA (59-60) APA1 (71) NASW (79)
 Health care providers should be familiar with relevant state and federal regulations governing information about substance abuse treatment. 	AAP (75) NASW (79)	
 School health personnel should be familiar with federal and state laws and local educational policies with respect to confidentiality. 	NASP (54-55, 78-79) NASW (79)	
Emergency health care providers should be knowledgeable about federal and state laws and departmental policies regarding treatment of minors.	AAP (79-81) ACEP (79-81)	
Staff in jails, prisons, and juvenile confinement facilities should be informed about confidentiality laws.	ANA (59-60, 71)	
☐ Adolescents and parents should understand relevant laws and regulations about confidentiality for minors.	AAFP (44) AAP (44)	ACOG (44)
☐ While parental involvement in adolescent health care is desirable, it may not always be feasible. Mandatory parental consent or notification should not be legislated.	AAFP (44-46) AAP (44-46)	ACOG (44-46) SAM (44-46, 55-58)
Legal barriers and deference to parental involvement should not impede access to needed health care.	AAFP (44) AAP (44)	ACOG (44)
Adolescents should be able to receive confidential services based on their own consent whenever limitations on confidentiality would serve as an obstacle impeding their access to care. Federal and state laws should support confidential access to health care for adolescents in these circumstances.	SAM (55)	
Adolescents should be encouraged to involve their parents and other trusted adults in reproductive health care decisions, but this should not be mandated through parental consent or notification laws.	AAFP (61) AAP (61-63) ACOG (61)	AMA (65) APHA (65-67) SAM (61, 68)
☐ Health care providers should advocate for public policies that ensure and protect adolescents' confidential access to health care.	ACOG (50-52) AMA (53)	SAM (55)
 Laws and regulations that are unduly restrictive of adolescents' confidential access to health services should be revised. 	AAFP (44) AAP (44)	ACOG (44, 63-64)
Efforts to undermine guarantees of confidentiality for adolescents should be opposed.	AAFP (44-46) AAP (44-46) ACOG (44-46)	APHA (66-67) SAM (44-46)

ii See page ii for the key to abbreviations of the names of the organizations cited in this table. Because the American Psychiatric Association and the American Psychological Association are each abbreviated as APA, they are listed here as APA1 and APA2, respectively.

ji The statements in this table are intended to provide a general thesis of the organizations' policy statements. Please refer to the page numbers indicated in the table for the precise language adopted by each organization and for appropriate citations to the source material.

Table 8: Policy Statements About Federal, State, and Local Laws that Protect Adolescents' Access to Confidential Health Services (cont'd)

	Organizations with Relevant Policies (corresponding page numbers in this Compendium)
■ Laws that allow minors to give their own consent for health care and that protect the confidentiality of adolescent's health information are fundamentally necessary to allow the health care professional to provide appropriate care and should be maintained. Efforts to repeal minor consent laws or to place limits on the confidentiality of services for minor patients should be opposed.	SAM (55-56)
 Legal barriers which restrict adolescents' access to confidential contraceptive and reproductive health services should be removed. 	ACOG (63-64) APHA (66-68)
■ Efforts should be made to clarify or change laws regarding parental consent in those states where the legality of providing contraceptive services without parental consent is in doubt.	APHA (66-68)
Health care providers should support legislation to allow minors to consent to services for the prevention, diagnosis, and treatment of STIs, including HIV.	AMA (70)

- □ The medical profession has long subscribed to a body of ethical statements developed primarily for the benefit of the patient. As a member of this profession, a physician must recognize responsibility to patients first and foremost, as well as to society, to other health professionals, and to self. The following Principles adopted by the American Medical Association are not laws, but standards of conduct which define the essentials of honorable behavior for the physician. [...] A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy within the constraints of the law. ^{58,3,11,68}
- ☐ The physician shall keep in confidence whatever she/he may learn about a patient in the discharge of professional duties. Information shall be divulged by the physician when required by law or when authorized by the patient. ^{65,3}
- ☐ Individuals have the right to be guaranteed the protection of the confidentiality of their relationship with their mental health and substance abuse professional, except when laws or ethics dictate otherwise. Any disclosure to another party will be time limited and made with the full written, informed consent of the individuals. Individuals shall not be required to disclose confidential, privileged or other information other than: diagnosis, prognosis, type of treatment, time and length of treatment, and cost. Entities receiving information for the purpose of benefits determination, public agencies receiving information for health care planning, or any other organization with legitimate right to information will maintain clinical information in confidence with the same rigor and be subject to the same penalties for violation as is the direct provider of care. Information technology will be used for transmission, storage, or data management only with methodologies that remove individual identifying information and assure the protection of the individual's privacy. Information should not be transferred, sold, or otherwise utilized. 34
- □ The medical profession has long recognized the ethical principle that communication between a patient and physician should be treated as confidential and should not be revealed by the physician to any third party without the patient's consent or unless required by law. The physician/patient privilege is a legal doctrine that recognizes and protects the confidential nature of communication between patients and their physicians. Accordingly, the American Academy of Family Physicians opposes any effort to erode or eliminate the physician/patient privilege. ¹⁰
- □ A confidential relationship between physician and patient is essential for the free flow of information necessary for sound medical care. Only in a setting of trust can a patient share the private feelings and personal history that enable the physician to comprehend fully, to diagnose logically and to treat properly. The AAFP believes that patient confidentiality must be protected. Historically, the privileged nature of communications between physician and patient has been a safeguard for the patient's personal privacy and constitutional rights. Though not absolute, the privilege is protected by legislative action and case law. However, data sharing across state lines is

American Medical
Association also endorsed by
the American Academy of
Child & Adolescent
Psychiatry, American
Academy of Family
Physicians, and the American
Psychiatric Association

Statement of the American
Osteopathic Association, also
endorsed by the American
Academy of Child &
Adolescent Psychiatry

American Nurses
Association, American
Psychiatric Association,
American Psychological
Association, National
Association of Social
Workers, and nine other
organizations

American Academy of Family Physicians

American Academy of Family Physicians

American Academy of Family Physicians (cont'd)

difficult given differing state patient privacy/confidentiality requirements. This Academy believes that state and federal legislators and jurists should seek a greater degree of standardization by recognizing the following principles regarding the privacy of medical information: a. The right to privacy is personal and fundamental. b. The privacy of medical information maintained by physicians is privileged. c. The patient should have a right of access to, and correction of, medical records. The right of access is not absolute. For example, in rare cases where full and direct disclosure to the patient might harm the patient's mental and/or physical well-being, access may be extended to his/her designated representative, preferably a physician.

- d. The privacy of adolescent minors should be respected. Parents should not, in some circumstances, have unrestricted access to the adolescent's medical records. Confidentiality must be maintained particularly in areas where the adolescent has the legal right to give consent.
- e. Medical information may have legitimate purposes outside of the physician/patient relationship, such as, billing, quality improvement, quality assurance, population-based care, patient safety, etc. However, patients and physicians must authorize release of any personally identifiable information to other parties. Third party payer and self-insured employer policies and contracts should explicitly describe the patient information that may be released, the purpose of the information release, the party who will receive the information, and the time period limit for release. Policies and contracts should further prohibit secondary information release without specific patient and physician authorization. f. Any disclosure of medical record information should be limited to information necessary to accomplish the purpose for which disclosure is made. Sensitive or privileged information may be excluded at the option of the physician unless the patient provides specific authorization for release. Photocopying of the medical record should not be allowed without the specific approval of the physician. g. Disclosure may be made for use in conducting legal medical records audits provided that stringent safeguards to prevent individual, medical identifiability are maintained.
- h. Policy exceptions which permit medical records release: 1. To another physician who is being consulted in connection with the treatment of the individual by the medical-care provider; 2. In compelling circumstances affecting the health and safety of an individual; 3. Pursuant to a court order or statute that requires the physician to report specific diagnoses to a public health authority; and 4. Pursuant to a court order or statute that requires the release of the medical record to a law enforcement agency or other legal authority.
- i. Electronic health information communication systems must be equipped with appropriate safeguards (e.g., encryption; message authentication, user verification, etc.) to protect physician and patient privacy. Individuals with access to electronic systems should be subject to clear, explicit, mandatory policies and procedures regarding the entry, management, storage, transmission and distribution of patient information.⁹

☐ The American College of Emergency Physicians believes that all physicians have an important ethical and legal duty to guard and respect the confidential nature of the personal information conveyed during the patientphysician encounter. Emergency physicians implicitly promise to preserve patient confidentiality, a promise that in turn promotes patients' autonomy, privacy, and trust in their emergency physicians. ACEP believes patient confidentiality is an important but not absolute principle. Confidential patient information may be disclosed when patients or their legal surrogates agree to disclosure, when mandated by law, or when there exist overriding and compelling grounds for disclosure, such as the prevention of substantial harm to identifiable other persons. ACEP also acknowledges that there are circumstances in which no societal consensus exists about whether to disclose patient information. Specific problem areas include but are not limited to cases involving minors, drug testing, employee health, perpetrators and victims of violent crimes, medical records, the media, and communicable and sexually transmitted diseases. Such cases can require an extraordinary degree of sensitivity, discretion, and judgment on the part of emergency physicians.⁴¹

Emergency Physicians

American College of

□ Emergency physicians should be compassionate and truthful in all of their communications with patients. Emergency physicians also have a responsibility to protect the confidentiality of patient information. Sensitive information may only be disclosed when such disclosure is necessary to carry out a stronger conflicting duty, such as a duty to protect an identifiable third party from serious harm or to comply with a just law. ³⁸

American College of Emergency Physicians

□ Privacy refers to the ability of the individual to maintain control over the time, place, manner, and extent to which information about one's self, beliefs, or person, is shared. Safeguarding privacy, respecting confidentiality and protecting against disclosure of information except when required by law or authorized by the client are essential to foster the establishment of a trusting relationship, preservation of the dignity and autonomy of the individual, and an increase in the likelihood that those who need services will seek them. ³⁵

American College Health Association

☐ The patient-physician relationship is the central focus of all ethical concerns, and the welfare of the patient should form the basis of all medical judgments. The obstetrician-gynecologist should serve as the patient's advocate and exercise all reasonable means to ensure that the most appropriate care is provided to the patient. The physician-patient relationship has an ethical basis and is built on confidentiality, trust, and honesty. [...] The obstetriciangynecologist has an obligation to obtain the informed consent of each patient. In obtaining informed consent for any course of medical or surgical treatment, the obstetrician-gynecologist should present to the patient, or to the person legally responsible for the patient, in understandable terms, pertinent medical facts and recommendations consistent with good medical practice. Such information should include alternate modes of treatment and the objectives, risks, benefits, possible complications, and anticipated results of such treatments. [...] The obstetrician-gynecologist should respect the rights of patients, colleagues, and others and safeguard patient information and confidences within the limits of the law. If during the process of providing information for consent it is known that results of a particular test or other information must be given to governmental authorities or other third

parties, that should be explained to the patient. 42

American College of Obstetricians and Gynecologists

American College of Physicians

Patients have a basic right to privacy that includes the information contained in patient medical records. Medical personnel who collect health information have a responsibility to protect patients from invasion of their privacy. [...] The very nature of medicine depends on the physician-patient relationship. Patients need to be treated in an environment in which they feel comfortable disclosing sensitive personal information to a physician that they trust. Otherwise, they may fail to fully disclose conditions and symptoms, thereby reducing the effectiveness of treatment and perhaps seriously imperiling their health. Or, they may avoid seeking care altogether for fear of negative consequences that could result from disclosure. 46

American College of Physicians

□ Confidentiality is a fundamental tenet of medical care. It is a matter of respecting the privacy of patients, encouraging them to seek medical care and discuss their problems candidly, and preventing discrimination on the basis of their medical conditions. The physician must not release information without the patient's consent (often termed a "privileged communication"). However, confidentiality, like other ethical duties, is not absolute. It may have to be overridden to protect individual persons or the public—for example, to warn sexual partners that a patient has syphilis or is infected with HIV—or to disclose information when the law requires it. Before breaching confidentiality, the physician should make every effort to discuss the issues with the patient. If breaching confidentiality is necessary, it should be done in a way that minimizes harm to the patient and that heeds applicable federal and state law. [...]

Physicians should be aware of the increased risk for invasion of patients' privacy and should help ensure confidentiality. Within their own institutions, physicians should advocate policies and procedures to secure the confidentiality of patient records.

Discussion of the problems of an identified patient by professional staff in public places (for example, in elevators or in cafeterias) violates confidentiality and is unethical. Outside of an educational setting, discussions of a potentially identifiable patient in front of persons who are not involved in that patient's care are unwise and impair the public's confidence in the medical profession. Physicians of patients who are well known to the public should remember that they are not free to discuss or disclose information about a patient's health without the explicit consent of the patient. [...] Ethically and legally, patients have the right to know what is in their medical records. Legally, the actual chart is the property of the physician or institution, although the information in the chart is the property of the patient. Most states have laws that guarantee the patient personal access to the medical record. The physician must release information to the patient or a third party at the request of the patient [...] To protect confidentiality, information should only be released with the written permission of the patient or the patient's legally authorized representative. [...]

To make health care decisions and work intelligently in partnership with the physician, the patient must be well informed. Effective patient-physician communication can dispel uncertainty and fear and can enhance healing and patient satisfaction. ⁴⁷

- □ Concern about the privacy of medical information has always been a tenet of responsible medical care. However, these concerns have been heightened in recent years by new forms of data that are highly sensitive and could, if discovered and used improperly, damage an individual's psychological well-being as well as their employability and insurability. [...] Organizations that deliver medical care, or conduct biomedical, epidemiologic or health services research, or retain medical data, such as health insurers, must be responsible and accountable for the development and implementation of appropriate policies to ensure protection of confidentiality of medical information through such mechanisms as adherence to accreditation standards and state laws and regulations, physical security safeguards, administrative policies and procedures, and electronic information security systems. These mechanisms should be reviewed by Institutional Review Boards. ⁴⁸
- American College of Preventive Medicine

☐ Our AMA affirms the following key principles that should be consistently implemented to evaluate any proposal regarding patient privacy and the confidentiality of medical information: (a) That there exists a basic right of patients to privacy of their medical information and records, and that this right should be explicitly acknowledged; (b) That patients' privacy should be honored unless waived by the patient in a meaningful way or in rare instances when strong countervailing interests in public health or safety justify invasions of patient privacy or breaches of confidentiality, and then only when such invasions or breaches are subject to stringent safeguards enforced by appropriate standards of accountability; (c) That patients' privacy should be honored in the context of gathering and disclosing information for clinical research and quality improvement activities, and that any necessary departures from the preferred practices of obtaining patients' informed consent and of de-identifying all data be strictly controlled; and (d) That any information disclosed should be limited to that information, portion of the medical record, or abstract necessary to fulfill the immediate and specific purpose of disclosure. 57

American Medical
Association also endorsed by
American College of
Preventive Medicine

☐ From ancient times, physicians have recognized that the health and wellbeing of patients depends upon a collaborative effort between physician and patient. Patients share with physicians the responsibility for their own health care. The patient-physician relationship is of greatest benefit to patients when they bring medical problems to the attention of their physicians in a timely fashion, provide information about their medical condition to the best of their ability, and work with their physicians in a mutually respectful alliance. Physicians can best contribute to this alliance by serving as their patients' advocate and by fostering these rights: (1) The patient has the right to receive information from physicians and to discuss the benefits, risks, and costs of appropriate treatment alternatives. Patients should receive guidance from their physicians as to the optimal course of action. Patients are also entitled to obtain copies or summaries of their medical records, to have their questions answered, to be advised of potential conflicts of interest that their physicians might have, and to receive independent professional opinions; (2) The patient has the right to make decisions regarding the health care that is recommended by his or her physician. Accordingly, patients may accept or refuse any recommended medical treatment; (3) The patient has the right to courtesy, respect, dignity, responsiveness, and timely attention to his or her needs; [and,] (4) The patient has the right to confidentiality. The physician

American Medical Association

American Medical Association (cont'd)

should not reveal confidential communications or information without the consent of the patient, unless provided for by law or by the need to protect the welfare of the individual or the public interest. ⁵³

American Medical Association

☐ The information disclosed to a physician during the course of the relationship between physician and patient is confidential to the greatest possible degree. The patient should feel free to make a full disclosure of information to the physician in order that the physician may most effectively provide needed services. The patient should be able to make this disclosure with the knowledge that the physician will respect the confidential nature of the communication. The physician should not reveal confidential communications or information without the express consent of the patient, unless required to do so by law. The obligation to safeguard patient confidences is subject to certain exceptions which are ethically and legally justified because of overriding social considerations. Where a patient threatens to inflict serious bodily harm to another person or to him or herself and there is a reasonable probability that the patient may carry out the threat, the physician should take reasonable precautions for the protection of the intended victim, including notification of law enforcement authorities. Also, communicable diseases and gun shot and knife wounds should be reported as required by applicable statutes or ordinances. 52

American Medical Association

☐ In the context of health care, emphasis has been given to confidentiality, which is defined as information told in confidence or imparted in secret. However, physicians also should be mindful of patient privacy, which encompasses information that is concealed from others outside of the patientphysician relationship. Physicians must seek to protect patient privacy in all of its forms, including (1) physical, which focuses on individuals and their personal spaces, (2) informational, which involves specific personal data, (3) decisional, which focuses on personal choices, and (4) associational, which refers to family or other intimate relations. Such respect for patient privacy is a fundamental expression of patient autonomy and is a prerequisite to building the trust that is at the core of the patient-physician relationship. Privacy is not absolute, and must be balanced with the need for the efficient provision of medical care and the availability of resources. Physicians should be aware of and respect the special concerns of their patients regarding privacy. Patients should be informed of any significant infringement on their privacy of which they may otherwise be unaware. 59

American Nurses Association

□ The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient. [...] The nurse safeguards the patient's right to privacy. The need for health care does not justify unwanted intrusion into the patient's life. The nurse advocates for an environment that provides for sufficient physical privacy, including auditory privacy for discussions of a personal nature and policies and practices that protect the confidentiality of information. [...] Associated with the right to privacy, the nurse has a duty to maintain confidentiality of all patient information. The patient's well-being could be jeopardized and the fundamental trust between patient and nurse destroyed by unnecessary access to data or by the inappropriate disclosure of identifiable patient information. The rights, well-being, and safety of the individual patient should be the primary factors in arriving at any professional judgment concerning the disposition of confidential information

received from or about the patient, whether oral, written or electronic. The standard of nursing practice and the nurse's responsibility to provide quality care require that relevant data be shared with those members of the health care team who have a need to know. Only information pertinent to a patient's treatment and welfare is disclosed, and only to those directly involved with the patient's care. Duties of confidentiality, however, are not absolute and may need to be modified in order to protect the patient, other innocent parties and in circumstances of mandatory disclosure for public health reasons. Information used for purposes of peer review, third-party payments, and other quality improvement or risk management mechanisms may be disclosed only under defined policies, mandates, or protocols. These written guidelines must assure that the rights, well-being, and safety of the patient are protected. In general, only that information directly relevant to a task or a specific responsibility should be disclosed. When using electronic communications, special effort should be made to maintain data security. ⁶²

American Nurses Association (cont'd)

☐ In keeping with the nursing profession's commitment to patient advocacy and the trust that is essential to the preservation of the high quality of care patients have come to expect from registered nurses, the American Nurses Association supports the following principles with respect to patient privacy and confidentiality[.] [1] A patient's right to privacy with respect to individually identifiable health information, including genetic information, should be established statutorily. Individuals should retain the right to decide to whom, and under what circumstances, their individually identifiable health information will be disclosed. Confidentiality protections should extend not only to health records, but also to all other individually identifiable health information, including genetic information, clinical research records, and mental health therapy notes. [2] Use and disclosure of individually identifiable health information should be limited. [3] A patient should have the right to access his or her own health information and the right to supplement such information so that they are able to make informed health care decisions, to correct erroneous information, and to address discrepancies that they perceive.

American Nurses Association

[4] Patients should receive written, easily understood notification of how their health records are used and when their individually identifiable health information is disclosed to third parties. [5] The use or disclosure of individually identifiable health information absent an individual's informed consent should be prohibited. Exceptions should be permitted only if a person's life is endangered, if there is a threat to the public, or if there is a compelling law enforcement need. In the case of such exceptions, information should be limited to the minimum amount necessary. [6] Appropriate safeguards should be developed and required for the use, disclosure and storage of personal health information. [7] Legislative or regulatory protections on individually identifiable health information should not unnecessarily impede public health efforts or clinical, medical, nursing, or quality of care research. [8] Strong and enforceable remedies for violations of privacy protections should be established, and health care professionals who report violations should be protected from retaliation. [9] Federal legislation should provide a floor for the protection of individual privacy and confidentiality rights, not a ceiling. Federal legislation should not preempt any other federal or state law or regulation that offers greater protection. 64

American Psychiatric Association

☐ 1. Psychiatric records, including even the identification of a person as a patient, must be protected with extreme care. Confidentiality is essential to psychiatric treatment. This is based in part on the special nature of psychiatric therapy as well as on the traditional ethical relationship between a physician and patient. Growing concern regarding the civil rights of patients and the possible adverse effects of computerization, duplication equipment, and data banks makes the dissemination of confidential information an increasing hazard. Because of the sensitive and private nature of the information with which the psychiatrist deals, he/she must be circumspect in the information that he/she chooses to disclose to others about a patient. The welfare of the patient must be a continuing consideration. 2. A psychiatrist may release confidential information only with the authorization of the patient or under proper legal compulsion. The continuing duty of the psychiatrist to protect the patient includes fully apprising him/her of the connotations of waiving the privilege of privacy. [...] 8. Psychiatrists at time may find it necessary, in order to protect the patient or the community from imminent danger, to reveal confidential information disclosed by the patient. 68

American Psychiatric Association

□ [C]onfidentiality is an essential element of high quality health care. Some patients refrain from seeking medical care or drop out of treatment in order to avoid any risk of disclosure of their records. And some patients simply will not provide the full information necessary for successful treatment. Patient privacy is particularly critical in ensuring high quality psychiatric care. Both the Surgeon General's Report on Mental Health and the US Supreme Court's Jaffee v. Redmond decision conclude that privacy is an essential requisite for effective mental health care. The Surgeon General's Report concluded that "people's willingness to seek help is contingent on their confidence that personal revelations of mental distress will not be disclosed without their consent." And in Jaffee, the Court held that "Effective psychotherapy depends upon an atmosphere of confidence and trust...For this reason the mere possibility of disclosure may impede the development of the confidential relationship necessary for successful treatment." [...] The right of consent is perhaps most important for those persons seeking and receiving mental health services. Mental health records can contain for the purpose of treatment particularly sensitive and potentially stigmatizing personal information if inappropriately disclosed. Considering the sensitivity of mental health records, patients should have the right to consent to their use and disclosure to insurers and other third parties. 66

American Psychological Association

☐ Psychologists respect the dignity and worth of all people, and the rights of individuals to privacy, confidentiality, and self-determination. Psychologists are aware that special safeguards may be necessary to protect the rights and welfare of persons or communities whose vulnerabilities impair autonomous decision making. [...]

Psychologists have a primary obligation and take reasonable precautions to protect confidential information obtained through or stored in any medium, recognizing that the extent and limits of confidentiality may be regulated by law or established by institutional rules or professional or scientific relationship. [...]

(a) Psychologists discuss with persons (including, to the extent feasible, persons who are legally incapable of giving informed consent and their legal

representatives) and organizations with whom they establish a scientific or professional relationship (1) the relevant limits of confidentiality and (2) the foreseeable uses of the information generated through their psychological activities. (b) Unless it is not feasible or is contraindicated, the discussion of confidentiality occurs at the outset of the relationship and thereafter as new circumstances may warrant. (c) Psychologists who offer services, products, or information via electronic transmission inform clients/patients of the risks to privacy and limits of confidentiality. [...]

- (a) Psychologists include in written and oral reports and consultations, only information germane to the purpose for which the communication is made. (b)Psychologists discuss confidential information obtained in their work only for appropriate scientific or professional purposes and only with persons clearly concerned with such matters. [...]
- (a) Psychologists may disclose confidential information with the appropriate consent of the organizational client, the individual client/patient, or another legally authorized person on behalf of the client/patient unless prohibited by law. (b) Psychologists disclose confidential information without the consent of the individual only as mandated by law, or where permitted by law for a valid purpose such as to (1) provide needed professional services; (2) obtain appropriate professional consultations; (3) protect the client/patient, psychologist, or others from harm; or (4) obtain payment for services from a client/patient, in which instance disclosure is limited to the minimum that is necessary to achieve the purpose. [...]
- (a) Psychologists maintain confidentiality in creating, storing, accessing, transferring, and disposing of records under their control, whether these are written, automated, or in any other medium. (b) If confidential information concerning recipients of psychological services is entered into databases or systems of records available to persons whose access has not been consented to by the recipient, psychologists use coding or other techniques to avoid the inclusion of personal identifiers. (c) Psychologists make plans in advance to facilitate the appropriate transfer and to protect the confidentiality of records and data in the event of psychologists' withdrawal from positions or practice. [...]

When obtaining informed consent to therapy [...] psychologists inform clients/patients as early as is feasible in the therapeutic relationship about the nature and anticipated course of therapy, fees, involvement of third parties, and limits of confidentiality and provide sufficient opportunity for the client/patient to ask questions and receive answers. ⁶⁹

Except for very narrow purposes (including public health surveillance) APHA supports the fundamental right of individuals' health information to remain private. Not only is this a basic right of privacy, we believe, but it is essential to the public health that individuals perceive their personal health information is being handled with care. ⁷²

American Psychological
Association (cont'd)

American Public Health Association

National Association of Social Workers

- (a) Social workers should respect clients' right to privacy. Social workers should not solicit private information from clients unless it is essential to providing services or conducting social work evaluation or research. Once private information is shared, standards of confidentiality apply. (b) Social workers may disclose confidential information when appropriate with valid consent from a client or a person legally authorized to consent on behalf of a client.
 - (c) Social workers should protect the confidentiality of all information obtained in the course of professional service, except for compelling professional reasons. The general expectation that social workers will keep information confidential does not apply when disclosure is necessary to prevent serious, foreseeable, and imminent harm to a client or other identifiable person. In all instances, social workers should disclose the least amount of confidential information necessary to achieve the desired purpose; only information that is directly relevant to the purpose for which the disclosure is made should be revealed.
 - (d) Social workers should inform clients, to the extent possible, about the disclosure of confidential information and the potential consequences, when feasible before the disclosure is made. This applies whether social workers disclose confidential information on the basis of a legal requirement or client consent. (e) Social workers should discuss with clients and other interested parties the nature of confidentiality and limitations of clients' right to confidentiality. Social workers should review with clients circumstances where confidential information may be requested and where disclosure of confidential information may be legally required. This discussion should occur as soon as possible in the social worker-client relationship and as needed throughout the course of the relationship [...]
 - (h) Social workers should not disclose confidential information to third-party payers unless clients have authorized such disclosure. (i) Social workers should not discuss confidential information in any setting unless privacy can be ensured. Social workers should not discuss confidential information in public or semipublic areas such as hallways, waiting rooms, elevators, and restaurants.
 - (j) Social workers should protect the confidentiality of clients during legal proceedings to the extent permitted by law. When a court of law or other legally authorized body orders social workers to disclose confidential or privileged information without a client's consent and such disclosure could cause harm to the client, social workers should request that the court withdraw the order or limit the order as narrowly as possible or maintain the records under seal, unavailable for public inspection. (k) Social workers should protect the confidentiality of clients when responding to requests from members of the media.
 - (l) Social workers should protect the confidentiality of clients' written and electronic records and other sensitive information. Social workers should take reasonable steps to ensure that clients' records are stored in a secure location and that clients' records are not available to others who are not authorized to have access. (m) Social workers should take precautions to ensure and maintain the confidentiality of information transmitted to other parties through the use of computers, electronic mail, facsimile machines, telephones

and telephone answering machines, and other electronic or computer technology. Disclosure of identifying information should be avoided whenever possible. (n) Social workers should transfer or dispose of clients' records in a manner that protects clients' confidentiality and is consistent with state statutes governing records and social work licensure. (o) Social workers should take reasonable precautions to protect client confidentiality in the event of the social worker's termination of practice, incapacitation, or death.

- (p) Social workers should not disclose identifying information when discussing clients for teaching or training purposes unless the client has consented to disclosure of confidential information. (q) Social workers should not disclose identifying information when discussing clients with consultants unless the client has consented to disclosure of confidential information or there is a compelling need for such disclosure. (r) Social workers should protect the confidentiality of deceased clients consistent with the preceding standards. [...]
- (a) Social workers should provide clients with reasonable access to records concerning the clients. Social workers who are concerned that clients' access to their records could cause serious misunderstanding or harm to the client should provide assistance in interpreting the records and consultation with the client regarding the records. Social workers should limit clients' access to their records, or portions of their records, only in exceptional circumstances when there is compelling evidence that such access would cause serious harm to the client. Both clients' requests and the rationale for withholding some or all of the record should be documented in clients' files. (b) When providing clients with access to their records, social workers should take steps to protect the confidentiality of other individuals identified or discussed in such records. [...]

Social workers should respect confidential information shared by colleagues in the course of their professional relationships and transactions. Social workers should ensure that such colleagues understand social workers' obligation to respect confidentiality and any exceptions related to it. ⁸⁶

□ Whether as independent or agency-based practitioners, social workers should have available for all new clients written information about records, release of records, information required by managed care and other insurers if applicable, and the legal and ethical limits of confidentiality or privileged communication and should ensure that clients understand these issues. Social workers should become familiar with HIPAA. [...] The following five client principles should guide social workers: 1. Clients should be used as the primary source of information about themselves. 2. Only information that is demonstrably related to the solution of clients' problems should be received, recorded, or released. 3. Clients will be fully informed about the implications of sharing personal information, including the ethical and legal obligations of the social worker to respect privacy and protect the confidentiality and legal constraints and limitations that impinge on both the client and the social worker. 4. Clients' informed and authorized consent will be a prerequisite to transmitting information to or requesting it from third parties. 5. Clients will be appraised of the kind of records maintained by the social worker or agency and should have the right to verify the accuracy of the records personally. 87

National Association of Social Workers (cont'd)

National Association of Social Workers

American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Obstetricians and Gynecologists, and two other organizations □ Adolescents tend to underutilize existing health care resources. The issue of confidentiality has been identified, by both providers and young people themselves, as a significant access barrier to health care. Adolescents in the United States, while generally considered healthy, have a range of problems, including some of such severity as to jeopardize their development and health, their future opportunities and even their lives. To illustrate, there is an urgent need to reduce the incidence of adolescent suicide, substance abuse, and sexually transmitted diseases and unintended pregnancy.

As the primary providers of health care to adolescents, we urge the following principles for the guidance of our professional members and for broad consideration in the development of public policy: 1. Health professionals have an ethical obligation to provide the best possible care and counseling to respond to the needs of their adolescent patients. 2. This obligation includes every reasonable effort to encourage the adolescent to involve parents, whose support can, in many circumstances, increase the potential for dealing with the adolescent's problems on a continuing basis. 3. Parents are frequently in a patient relationship with the same providers as their children or have been exercising decision-making responsibility for their children with these providers. At the time providers establish an independent relationship with adolescents as patients, the providers should make this new relationship clear to parents and adolescents with regard to the following elements: The adolescent will have an opportunity for examination and counseling apart from parents, and the same confidentiality will be preserved between the adolescent patient and the provider as between the parent/adult and the provider. The adolescent must understand under what circumstances (e.g., life-threatening emergency), the provider will abrogate this confidentiality. Parents should be encouraged to work out means to facilitate communication regarding appointments, payment, or other matters consistent with the understanding reached about confidentiality and parental support in this transitional period when the adolescent is moving toward self-responsibility for health care. 4. Providers, parents, and adolescents need to be aware of the nature and effect of laws and regulations in their jurisdictions that introduce further constraints on these relationships. Some of these laws and regulations are unduly restrictive and in need of revision as a matter of public policy. Ultimately, the health risks to the adolescent are so impelling that legal barriers and deference to parental involvement should not stand in the way of needed health care. 15

American Academy of Pediatrics, also endorsed by the American Academy of Family Physicians, the American College of Obstetricians and Gynecologists, and the Society for Adolescent Medicine □ The American Academy of Pediatrics and the endorsing organizations [AAFP, ACOG, and SAM] firmly believe that parents should be involved in and responsible for assuring medical care for our children. Moreover, we would agree that as parents we ordinarily act in the best interests of our children and that minors benefit from our advice and the emotional support we provide as parents. We strongly encourage and hope that adolescents communicate with and involve their parents and/or other trusted adults in important health care decisions affecting their lives. These discussions include such issues as substance abuse, mental health and pregnancy and pregnancy termination. We know and research confirms that most adolescents do so voluntarily. This is predicated not by laws but on the

quality of their relationships. By its very nature family communication is a family responsibility. Adolescents who live in warm, loving, caring environments, who feel supported by their parents, will in most instances communicate with their parents in a crisis including the disclosure of a pregnancy or other urgent health concerns. However, even adolescents reared in the best of household environments will at times be unwilling to make full disclosure of their behaviors because they do not wish to disappoint and hurt loving and caring parents.

Family communication about health care decisions is the desired goal, and health care professionals are able to assist in this effort. Allowing confidentiality of care for adolescents does not preclude the involvement of parents, as it is sometimes presumed. To the contrary, research has shown that adolescents often voluntarily share information with their parents and clinical experience confirms that this often occurs after they consult privately with their health care provider.

Ensuring confidential care is about striking an important balance among parents, providers and the adolescent patient. While there may be circumstances when it is necessary and appropriate for the health care provider to inform parents or guardians of certain health problems facing a minor (e.g., life-threatening emergency) there is a critical need to ensure that an adolescent's health information is protected. Providing confidential care does not preclude working toward the goal of family communication.

Pediatricians, parents and policy makers know well the number of adolescents that are beginning to use illicit drugs, alcohol and become sexually active. What may start as experimentation with friends often leads to long term dependencies, accidents, injuries, sexually transmitted disease and a myriad of other physical and behavioral issues. In the infrequent cases where communication between adolescents and their parents can not be facilitated, many of these negative outcomes can be avoided if the adolescent has access to confidential health care.

My role as a pediatrician is to support, encourage, strengthen and enhance parental communication and involvement in adolescent decisions without compromising the ethics and integrity of my relationship with adolescent patients. Health professionals have an obligation to provide the best possible care to respond to the needs of their adolescent patients. [...]

The stated intent of those who support mandatory parental consent or notification legislation [...] is that it enhances family communication as well as parental involvement and responsibility. However, the evidence does not support that these laws have that desired effect. To the contrary, there is evidence that these laws may have an adverse impact on some families and that [they] increas[e] the risk of medical and psychological harm to adolescents. According to the AAP, "[i]nvoluntary parental notification can precipitate a family crisis characterized by severe parental anger and rejection of the minor and her partner. One third of minors who do not inform parents already have experienced family violence and fear it will recur. Research on abusive and dysfunctional families shows that violence is at its worse during a family member's pregnancy and during the adolescence of the family's

American Academy of Pediatrics, also endorsed by the American Academy of Family Physicians, the American College of Obstetricians and Gynecologists, and the Society for Adolescent Medicine (cont'd)

American Academy of Pediatrics, also endorsed by the American Academy of Family Physicians, the American College of Obstetricians and Gynecologists, and the Society for Adolescent Medicine (cont'd) children." It is for these and other reasons that the American Academy of Pediatrics and other organizations represented [in this testimony] oppose [legislation] that will undermine federal guarantees of confidentiality for adolescents receiving health care services. [...]

[We] firmly believe that young people must have access to confidential health care services. Every one of our states' laws also provides confidential access to some services for young people, whether for sexually transmitted diseases (STDs), drug addiction or reproductive health care. Concern about confidentiality is one of the primary reasons young people delay seeking health services for sensitive issues, whether for substance use, an unintended pregnancy or for other reasons. While parental involvement is very desirable, and should be encouraged, it may not always be feasible and it should not be legislated. Young people must be able to receive accurate diagnosis and appropriate treatment expeditiously and confidentially. [...]

Most adolescents will seek medical care with their parent or parents' knowledge. Making services contingent on mandatory parental involvement (either parental consent or notification) however, may drastically affect adolescent decision-making. Mandatory parental consent or notification reduces the likelihood that young people will seek timely treatment for sensitive health issues. In a regional survey of suburban adolescents, only 45 percent said they would seek medical care for sexually transmitted diseases, drug abuse or birth control if they were forced to notify their parents.

A teen struggling with concerns over his or her substance use, emotional well-being or sexual health may be reluctant to share these concerns with a parent for fear of embarrassment, disapproval, or possible violence. A parent or relative may even be the cause or focus of the teen's emotional or physical problems. The guarantee of confidentiality and the adolescent's awareness of this guarantee are both essential in helping adolescents to seek health care. ¹³

American Academy of Child & Adolescent Psychiatry

☐ The issues of consent, confidentiality, professional responsibility, authority and behavior must be viewed within the context of development and the overlapping and potentially conflicting rights of the child or adolescent, of the parents, and of society. [...] The primary concerns of child and adolescent psychiatrists are the welfare and the optimum development of the individual child or adolescent patient or of the population of children and adolescents being served. [...] Child and adolescent psychiatric evaluations, treatment, and prevention activities may involve the participation and ideally the concurrence of many people. In attempting to develop such an arrangement, the child and adolescent psychiatrist should seek to provide the patients themselves and those involved in their care and/or treatment (parents or guardians, and where appropriate, the teacher and school, court or correctional agency, physicians and others) as thorough an understanding as can usefully be grasped and therapeutically utilized in the care of the child. Specific confidences of the patient and the parents or guardians and others involved should be protected unless this course would involve untenable risks or betrayal of care-taking responsibility. [...]

There are situations where a difference exists in the views of a child or adolescent and parents or guardians regarding a professional judgment or recommendation. This may involve evaluation, treatment or prevention efforts, or the release of information. In such circumstances, the child and adolescent psychiatrist will work toward helping family members to resolve these differences. During this process, the child and adolescent psychiatrist will keep constantly in mind the well-being and developmental potential of the child or adolescent, the nature of family relationships and the responsibilities and the legal and moral prerogatives of both parents and offspring. [...]

It is often necessary and appropriate that others outside of the family provide information and that they also be informed regarding professional judgments, opinions, recommendations, and actions. The release of any information regarding a minor unemancipated child or adolescent to persons outside the family (including the non-custodial parent) requires the agreement of parents or guardians. Regardless of the locus of decision, the child and adolescent psychiatrist will attempt to inform the child or adolescent of the need and intent to release information and will seek his/her concurrence even though such an agreement is not required. Specific confidences of child or adolescent patients and of parents or guardians should be protected unless doing so would involve untenable risks or betrayal of care-taking responsibilities. [...]

It is necessary that the child or adolescent, within his/her capacity for understanding, be clearly appraised of confidentiality in regard both to his/her own communication and those of parents or guardians. He/she should also be informed of the limits to the general principle of confidentiality that the sharing of care-taking responsibilities requires. [...]

Where required to do so by the laws of a state, as in cases of child abuse and neglect, or in other situations where the safety and welfare of the patient, children, or others are in jeopardy, the child and adolescent psychiatrist may divulge confidences. However, in such cases the parties involved must be thoroughly informed in advance of these requirements. [...]

In those situations which a child and adolescent psychiatrist agrees to evaluate a child, adolescent, parent(s) or other individuals or situations for administrative, legal, or quasi-legal purpose, all parties should be informed of the nature and intent of the evaluation, and the lack of any ability to protect confidences. [...]

Child and adolescent psychiatrists must notify patients and their families at the onset of the constraints of confidentiality under health plan contracts. Families should be informed of the potential ramifications of requests for records by health plans, and their consent for releasing information should be obtained. ³

American Academy of Child & Adolescent Psychiatry (cont'd)

American Academy of Child & Adolescent Psychiatry

☐ From the clinician's point of view, many utilization management reviewers are intruding into clinical practice in a way that has a negative effect on quality of care by disturbing the potentially fragile treatment alliance, by compromising confidentiality, and by inappropriately mixing fiscal and medical treatment concerns. This appears to be particularly true for the child or adolescent who needs treatment for a serious psychiatric illness or drug or alcohol problem. Improperly managed utilization review may grossly compromise the ongoing treatment process so that significant psychiatric or physical harm may result. [...] [5] Parents of minors and when appropriate, patients, must be informed fully of the utilization review process. This is a shared responsibility of the utilization management company to provide necessary general information and the hospital and/or physician in obtaining informed consent for their participation in providing the information. [6] The utilization management organization should have policies in force to ensure that no more information is obtained than is necessary to make appropriate reviews, that the information is held confidential, and that it is used only for the purpose of making a determination on the medical necessity and level of care for a particular episode of illness. [...] [11] Interviewing patients and family members, or discussing or recommending a specific course of treatment, is an unacceptable intrusion into the physician [-patient relationship unless] authorized by the attending physician, the patient and the family and done in accordance with medical staff policy. 7

American Academy of Family Physicians

□ Concerns about confidentiality may discourage adolescents from seeking necessary medical care and counseling, and may create barriers to open communication between patient and physician. Protection of confidentiality is needed to appropriately address issues such as depression, suicide, substance abuse, domestic violence, unintended pregnancy and sexual orientation.

When caring for an adolescent patient: 1. The physician should offer the adolescent an opportunity for examination and counseling separate from parents/guardians, and their privacy should be respected. 2. The physician should make a reasonable effort to encourage the adolescent to involve parents or guardians in healthcare decisions. 3. The physician should educate parents to encourage their adolescents toward personal responsibility in health care, and facilitate communication regarding appointments and payments, in a manner supportive of the adolescent's rights to confidentiality. 4. Every effort should be made to maintain confidentiality. The limits on what can be guaranteed should be clearly discussed. Information that would suggest someone is in danger, evidence of abuse or diagnosis of certain communicable diseases must be reported to the proper authorities. Billing and insurance information often cannot be kept confidential from the guarantor of payment.

Since state laws and regulations vary, family physicians should be aware of their community's standards regarding adolescent confidentiality. In general, especially in areas where the adolescent has the legal right to give consent, confidentiality must be maintained. Ultimately, the judgment of the physician should prevail in the best medical interest of the patient. ⁸

- ☐ The privacy of adolescent minors should be respected. Parents should not, in some circumstances, have unrestricted access to the adolescent's medical records. Confidentiality must be maintained particularly in areas where the adolescent has the legal right to give consent. 9
- American Academy of Family Physicians
- □ As children develop, they should gradually become the primary guardians of personal health and the primary partners in medical decision-making, assuming responsibility from their parents. [...] In situations [...] that involve adolescents and young adults, the Academy encourages physicians to obtain the informed consent of the patient in most instances. [...] Such patients frequently have decision-making capacity and the legal authority to accept or reject interventions, and, in that event, no additional requirement to obtain parental permission exists. However, the Academy encourages parental involvement in such cases, as appropriate.

American Academy of Pediatrics

Review of the limited relevant empirical data suggests that adolescents, especially those age 14 and older, may have as well developed decisional skills as adults for making informed health care decisions. Ethical and legal factors (i.e., confidentiality and/or privacy), suggest that the physician involve parents after appropriate discussion with the adolescent elicits his or her permission to do so. In some cases in which the patient has no legal entitlement to authorize treatment, the physician may have a legal obligation in some jurisdictions to obtain parental permission or to notify parents in addition to obtaining the patient's consent. An adolescent's refusal of consent in cases such as these may well be legally (and ethically) binding. ²³

American Academy of Pediatrics

- ☐ Health care professionals who practice family-centered care recognize the vital role that families play in ensuring the health and well-being of children and family members of all ages. These practitioners acknowledge that emotional, social, and developmental support are integral components of health care. They respect each child and family's innate strengths and view the health care experience as an opportunity to build on these strengths and support families in their caregiving and decision-making roles. Familycentered approaches lead to better health outcomes and wiser allocation of resources as well as greater patient and family satisfaction. Family-centered care in pediatrics is based on the understanding that the family is the child's primary source of strength and that the child's and family's perspectives and information are important in clinical decision making. Family-centered practitioners are keenly aware that health care experiences can enhance parents' confidence in their roles and, over time, increase the competence of children and young adults to take responsibility for their own health care, particularly in anticipation of the transition to adult service systems. [...]
 - 3. Working with families in decision making and information sharing in all practice settings should always take into account the older child's and young adult's capacity for independent decision making and right to privacy and confidentiality. 4. Parents and guardians should be offered the option to be present with their child during medical procedures and offered support before, during, and after the procedure.

American Academy of Pediatrics (cont'd)

5. Pediatricians should promote the active participation of all children in the management and direction of their own health care, beginning at an early age and continuing into adult health care. ²⁰

American Academy of Pediatrics

□ Although confidentiality is important in adolescent health care, for adolescents at risk to themselves or others, confidentiality must be breached. Pediatricians need to inform the appropriate persons when they believe an adolescent is at risk of suicide. [...] In addition to an in-depth psychological evaluation of the adolescent, family members should be interviewed to obtain additional information to help explain the adolescent's suicidal thoughts or attempt. This information includes detailed questions about the adolescent's medical, emotional, social, and family history with special attention to signs and symptoms of depression, stress, and substance abuse. With parental permission and adolescent assent, teachers and family friends also may provide useful information if confidentiality is not breached. ³⁰

American Academy of Pediatrics

□ It is important for pediatricians to develop office policies that assure confidentiality. State requirements and standards of practice should be reviewed and the development of clear, concise, and standardized office protocols for confidentiality should be developed for staff, patients, and parents. These policies should include information regarding when confidentiality must be waived, guidelines for reimbursement for services, medical record access, appointment scheduling, and office policy regarding information disclosure. ¹⁷

American Academy of Pediatrics

1. Pediatricians should understand and abide by legislative and regulatory requirements that address the confidentiality, secure transmission and storage, and public accessibility of patient medical information. 2. Pediatricians or their affiliated institutions should accept the responsibility for protecting the confidentiality of their medical records by personnel education, office procedures, and security strategies that are in compliance with federal standards. ²⁵

American Academy of Pediatrics

□ The purpose of [electronic medical record] EMR systems is to compile and centralize all pertinent information related to a child's medical and nonmedical care so as to ensure that optimal pediatric care is provided. In doing so, EMR systems have the capacity to improve the quality of care that children receive from their primary care pediatrician as well as from ancillary health care professionals. [...] Privacy laws regarding adolescents' medical information (especially sexual and mental health and behavior issues) vary from state to state, and policies addressing the protection of adolescents' health information vary from practice to practice. EMR systems must be able to respond to these privacy needs by allowing restriction of access to this information according to these laws and policies. ²⁹

American College of Obstetricians and Gynecologists

□ [1] Concern about confidentiality is a major obstacle to the delivery of health care to adolescents. [2] Physicians should address confidentiality issues with the adolescent patient to build a trusting relationship with her and to facilitate a candid discussion regarding her health and health-related behaviors.

[3] Physicians also should discuss confidentiality issues with the parent(s) or guardian(s) of the adolescent patient. Physicians should encourage their involvement in the patient's health and health care decisions and, when appropriate, facilitate communication between the two. [4] Physicians should develop office procedures to maintain adolescent patients' rights for confidentiality. All office staff should be aware of these procedures. [5] Physicians should be familiar with state and local statutes regarding the rights of minors to health care services and the federal and state laws that affect confidentiality. [...] [8] Health care providers should work to ensure that confidential services for adolescents are not compromised by legal and economic constraints. [...]

economic constraints. [...]

Most adolescents underuse existing health care services. A major obstacle to the delivery of health care to adolescents is their concern about confidentiality. Confidentiality refers to the privileged and private nature of information shared during a health care encounter. Although ensuring confidentiality is relatively simple when providing services to adults, providing the same degree of confidentiality to adolescents can be less straightforward. The legal status of a minor and legal requirements for

parental consent before the provision of medical services often encumber the

physician-patient relationship.

Confidentiality also may be compromised by economic considerations because few adolescents have the financial resources to pay for medical services and, therefore, may need parental or adult help in arranging payment. Although a few states allow adolescents to qualify for Medicaid on the basis of their own incomes, the majority of states consider family income and assets when determining eligibility. To supply such information, adolescents may need to consult with family members. Explanation of Benefits forms issued by indemnity insurers, managed care organizations, and Medicaid are sent to parent policyholders, which also can compromise the confidentiality of information and, therefore, a minor's access to health care services. [...]

[P]hysicians should work with the political process to eliminate laws unduly restrictive of confidential health services for adolescents.

Parents should be counseled that it is appropriate for the maturing adolescent girl to assume increasing responsibility for her health and health care. Adolescence is a period of significant change and maturation, and learning to make appropriate health care decisions is a major developmental task. Physicians can assist in this process by providing an environment in which adolescents can candidly discuss their concerns. Adolescents are more likely to develop trusting relationships with their health care providers when the issue of confidentiality has been addressed. A confidential relationship, in turn, facilitates the open disclosure of health histories and risky behaviors. The health and behavioral issues of adolescent patients can then be addressed with nonjudgmental counseling and medical intervention.

Physicians should stress to parents that they share a common goal—the health and well-being of the minor patient. The mutual trust that follows from this common goal will enhance and support the adolescent–physician

American College of Obstetricians and Gynecologists (cont'd)

American College of Obstetricians and Gynecologists (cont'd) relationship. The involvement of a concerned adult can contribute to the health and success of an adolescent. Providers should encourage and, when appropriate, facilitate communication between a minor and her parent(s).

Parents and adolescents should be informed, both separately and together, that they each have a private and privileged relationship with the provider. Additionally, they should be informed of any restrictions on the confidential nature of that relationship. For instance, the physician should explain that if the patient discloses any risk of bodily harm to herself or others, confidentiality will be breached. Furthermore, state laws may mandate the reporting of physical or sexual abuse of minors. [...] ⁴⁴

American College of Obstetricians and Gynecologists □ Billing mechanisms for services and procedures for insurance and other thirdparty reimbursement should ensure adolescent confidentiality. When these mechanisms and procedures compromise a patient's request for confidentiality, policies should be implemented allowing payment alternatives such as reduced fees, sliding scales, and timed installment payments and patient referral to a practice or agency where subsidized care is offered or both. ⁴³

American College of Physicians

□ In the care of the adolescent patient, family support is important. However, this support must be balanced with confidentiality and respect for the adolescent's autonomy in health care decisions and in relationships with health care providers. Physicians should be knowledgeable about state laws governing the right of adolescent patients to confidentiality and the adolescent's legal right to consent to treatment. ⁴⁷

American Medical Association Physicians who treat minors have an ethical duty to promote the autonomy of minor patients by involving them in the medical decision-making process to a degree commensurate with their abilities. When minors request confidential services, physicians should encourage them to involve their parents. This includes making efforts to obtain the minor's reasons for not involving their parents and correcting misconceptions that may be motivating their objections. Where the law does not require otherwise, physicians should permit a competent minor to consent to medical care and should not notify parents without the patient's consent. Depending on the seriousness of the decision, competence may be evaluated by physicians for most minors. When necessary, experts in adolescent medicine or child psychological development should be consulted. Use of the courts for competence determinations should be made only as a last resort.

When an immature minor requests contraceptive services, pregnancy-related care (including pregnancy testing, prenatal and postnatal care, and delivery services), or treatment for sexually transmitted disease, drug and alcohol abuse, or mental illness, physicians must recognize that requiring parental involvement may be counterproductive to the health of the patient. Physicians should encourage parental involvement in these situations. However, if the minor continues to object, his or her wishes ordinarily should be respected. If the physician is uncomfortable with providing services without parental involvement, and alternative confidential services are

available, the minor may be referred to those services. In cases when the physician believes that without parental involvement and guidance, the minor will face a serious health threat, and there is reason to believe that the parents will be helpful and understanding, disclosing the problem to the parents is ethically justified. When the physician does breach confidentiality to the parents, he or she must discuss the reasons for the breach with the minor prior to the disclosure.

For minors who are mature enough to be unaccompanied by their parents for their examination, confidentiality of information disclosed during an exam, interview, or in counseling should be maintained. Such information may be disclosed to parents when the patient consents to disclosure. Confidentiality may be justifiably breached in situations for which confidentiality for adults may be breached. [...] In addition, confidentiality for immature minors may be ethically breached when necessary to enable the parent to make an informed decision about treatment for the minor or when such a breach is necessary to avert serious harm to the minor. 50

☐ The 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 payors 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
- ☐ Parents should be encouraged to be intimately involved in the health supervision and education of their children. 60

care for adolescents and to help eliminate laws which restrict the availability

American Medical Association (cont'd)

American Medical Association

American Medical Association

of confidential care. 51

American Psychiatric Association

Careful judgment must be exercised by the psychiatrist in order to include, when appropriate, the parents or guardian in the treatment of a minor. At the same time, the psychiatrist must assure the minor proper confidentiality.⁶⁸

National Assembly on School-Based Health Care

☐ Children and adolescents have the right to quality, accessible, confidential, culturally appropriate, comprehensive health services. ⁷⁹

National Association of Pediatric Nurse Practitioners

NAPNAP affirms that with parental involvement and informed consent, children and adolescents should receive comprehensive primary care, including social services, mental health and health education with a focus on wellness. These services should be delivered within the context of the family and community including the school, with an emphasis on cultural awareness. ⁸¹

National Association of School Psychologists

- 3. School psychologists in all settings maintain professional relationships with children, parents, and the school community. Consequently, parents and children are to be fully informed about all relevant aspects of school psychological services in advance. The explanation should take into account language and cultural differences, cognitive capabilities, developmental level, and age so that it may be understood by the child, parent, or guardian. [...]
 - 9. School psychologists respect the confidentiality of information obtained during their professional work. Information is revealed only with the informed consent of the child, or the child's parent or legal guardian, except in those situations in which failure to release information would result in clear danger to the child or others. Obsolete confidential information will be shredded or otherwise destroyed before placement in recycling bins or trash receptacles.
 - 10. School psychologists discuss confidential information only for professional purposes and only with persons who have a legitimate need to know. School psychologists inform children and other clients of the limits of confidentiality. [...]
 - 2. School psychologists recognize the importance of parental support and seek to obtain that support by assuring that there is direct parent contact prior to seeing the child on an on-going basis. (Emergencies and "drop-in" self-referrals will require parental notification as soon as possible. The age and circumstances under which children may seek services without parental consent varies greatly; [school psychologists should] be certain to [...] "adhere to federal, state, and local laws and ordinances governing their practice and advocacy efforts. If regulations conflict with ethical guidelines, school psychologists seek to resolve such conflict through positive, respected, and legal channels including advocacy efforts involving public policy.") School psychologists secure continuing parental involvement by a frank and prompt reporting to the parent of findings and progress that conforms to the limits of previously determined confidentiality.
 - 3. School psychologists encourage and promote parental participation in designing services provided to their children. When appropriate, this includes linking interventions between the school and the home, tailoring parental involvement to the skills of the family, and helping parents gain

the skills needed to help their children. 4. School psychologists respect the wishes of parents who object to school psychological services and attempt to guide parents to alternative community resources. [...]

National Association of School Psychologists (cont'd)

6. School psychologists discuss the rights of parents and children regarding creation, modification, storage, and disposal of confidential materials that will result from the provision of school psychological services. ⁸⁴

National Association of Social Workers

□ 5. Youth health services should be provided in a professional and confidential manner with strict adherence to the concepts of self-determination and client confidentiality. Health services for youths must be provided in the context of the youth's peer group, family, and community. [...] 10. Health services for youths must use a multidisciplinary approach because of the interplay among individual characteristics, environmental factors, and social pressures that influence youth behavior.

Social workers should [...] empower adolescents, families, and communities through capacity-building activities to become active participants in the identification of adolescent health concerns; the creative resolution of these issues; and the advancement of adolescent, family, and societal well-being; [and] promote and adhere to the legal requirements that protect the health and safety of adolescents, families, and communities. ⁸⁵

Society for Adolescent Medicine

- ☐ Adolescents should be able to receive confidential services based on their own consent whenever limitations on confidentiality would serve as an obstacle impeding their access to care. Federal and state laws should support confidential access to health care for adolescents in these circumstances. Existing laws that provide for adolescents who are minors to give their own consent for health care and to receive services on a confidential basis should be maintained and fully implemented. Where additional protections are needed, they should be put in place. Health plans and providers should understand the relevant laws in their own jurisdictions, should implement administrative policies and procedures to maintain adolescents' confidentiality, and should inform adolescent patients and their parents about the scope and limitations of these protections. The existence of confidentiality protections for adolescents does not preclude, and sometimes helps to support, voluntary communication with parents, often with the assistance of a health care professional. Efforts to repeal minor consent laws or to place limits on the confidentiality of services for adolescents who are minors could undermine their access to essential services and should be opposed. 88
- Society for Adolescent Medicine
- □ Co-payments, if required at all, should be minimal; co-payments should not be imposed for services such as family planning, screening for sexually transmitted infections, or substance abuse counseling and treatment that are related to adolescents' high risk behaviors and that adolescents are reluctant to seek other than on a confidential basis. 94

Society for Adolescent Medicine

☐ On the basis of standards of clinical practice, research findings, principles of ethics, and law, the Society for Adolescent Medicine supports the following

Society for Adolescent Medicine (cont'd) positions with respect to confidentiality in the delivery of health services to adolescents. [1.] Confidentiality protection is an essential component of health care for adolescents because it is consistent with their development of maturity and autonomy and without it, some adolescents will forgo care. [2.] Confidential health care should be available, especially to encourage adolescents to seek health care for sensitive concerns and to ensure that they provide complete and candid information to their health care providers. [3.] Health care professionals should educate adolescent patients and their families about the meaning and importance of confidentiality, the scope of confidentiality protection, and the limits to confidentiality. [4.] Health care professionals should support effective communication between adolescents and their parents or other caretakers. Participation of parents in the health care of their adolescents should usually be encouraged, but should not be mandated. [5.] Health care professionals and delivery systems should review and, if necessary, revise their procedures (including scheduling, billing, and recordkeeping) to ensure that adolescents' privacy and the confidentiality of their health information are protected to the extent possible.[6.] Health care professionals should receive education and ongoing training to ensure that they know and understand the state and federal consent and confidentiality laws relevant to the delivery of health services to adolescents and have the skills to apply these laws when delivering clinical care. [7.] Laws that allow minors to give their own consent for all or some types of health care and that protect the confidentiality of adolescents' health care information are fundamentally necessary to allow health care professionals to provide appropriate health care to adolescents and should be maintained.[...]

The overall goal in clinical practice is to deliver appropriate high-quality health care to adolescent patients, while encouraging communication between adolescents and their parents or other trusted adults without betraying the adolescent's trust in the health care professional. When deciding how best to provide confidential health care to adolescents in specific clinical situations, health care providers need to take into account the following factors: [t]he patient's chronological age, cognitive and psychosocial development, other health-related behaviors, and prior family communication; [p]olicies of professional organizations that often support the provision of confidential health care to minors who request privacy for a broad range of health services, including treatment of STIs, contraceptive care, outpatient mental health services and outpatient substance abuse services; [1]aws that define emancipation, determine when a minor can consent to health care (e.g. state minor consent statutes), specify when parental consent or notification is required or permitted (e.g. often for abortion services), clarify the discretion of health care professionals to disclose information, and provide guidance on access to health care information and medical records; [t]he implications of the HIPAA Privacy Rule for the provision of adolescent health services; [and] [t]he limits of confidentiality (such as in situations of suspected physical or sexual abuse, suspected risk of suicide or homicide, and when public health laws require reporting certain diseases, e.g., Chlamydia, gonorrhea, TB, HIV), and strategies to involve the adolescent in appropriate plans for engaging parents or other trusted adults to assist with management of these situations.

Health care professionals must also consider a variety of practical issues. First, experienced clinicians recognize that candid and complete information can be gathered only by speaking with the adolescent patient alone, and by clarifying with whom the information will be shared. Beginning in early adolescence, routinely spending at least part of each visit alone with a patient conveys to the young patients and their parents that this is a standard part of adolescent health care. This also provides regular opportunities to develop a confidential relationship with adolescent patients and to discuss sensitive health topics in an open manner, and it can reassure parents that the health care professional is available to help address topics that they may have a difficult time discussing. Experiences of seasoned clinicians suggest that most parents, who are often very trusting of physicians with whom they have an established relationship, support this arrangement.

Second, routine discussions with adolescents and their parents about both the protections and the limitations of confidentiality are important. This conveys that a clinician is aware and respectful of privacy issues, educates adolescent patients and their parents about the guidelines for this aspect of care, and has beneficial effects on the patient-clinician relationship. It encourages open patient-clinician communication, which is essential for effective screening, accurate diagnosis, and risk-reduction counseling. This also increases the chance that adolescents will seek future health care for sensitive health concerns. It is important to recognize that adolescent patients are attentive to the specific content of messages. Clinicians should be as clear as possible about what can and cannot be managed privately and convey messages that adolescents both understand and can trust.

Third, clinicians need to be aware of system-level issues that may inadvertently break confidentiality and betray an adolescents' trust. Common problems are related to billing and reimbursement procedures, scheduling notification, and privacy of medical records. Strategies to provide appropriate confidential care within this context need to be developed where feasible. Alternatively, clinicians must be knowledgeable and prepared to refer patients who need confidential services to other sites where privacy can be assured. Attention to this issue at the level of health care systems, and within the context of wide-spread use of electronic medical records, is clearly needed.

Fourth, clinicians need to learn the skills to provide appropriate confidential adolescent health care while also encouraging communication with parents. This may involve strategies such as discussing with adolescent patients their perceptions of the pros and cons of communication with parents, helping adolescents to see the potential advantages of increased communication with parents, and offering to facilitate communication with parents in a way that is helpful to the adolescent patient. Giving consistent messages to parents that health care professionals expect parents to discuss a wide range of issues related to health with their adolescent children may be helpful, and parent questionnaires may be an efficient way to regularly reinforce this message. At the end of an adolescent visit, when "wrapping up" with the adolescent patient and the parent, it may be very useful to provide general anticipatory guidance counseling that, in fact, is tailored to needs identified during private discussion with an adolescent patient.

Society for Adolescent Medicine (cont'd)

Society for Adolescent Medicine (cont'd)

Finally, it is important to acknowledge that some adolescents do not have parents, parental support, or any meaningful connection with parents. Some adolescents have experienced abuse or neglect by parents, and have legitimate fears about future parental abuse, which may include being asked to leave one's home by parents. When clinicians encourage adolescents to communicate openly with their parents, it is important to ask about reasons for any reluctance to do so. There are times when it may be appropriate to identify and engage other trusted adults into management plans. ⁹¹

Society for Adolescent Medicine

□ Adolescents should be encouraged to involve their families in health decisions whenever possible; however, when such involvement is not in the best interest of the adolescent or when parental involvement may prevent the adolescent from seeking care, confidentiality must be assured. ⁸⁹

Policy Statements About Confidentiality Concerns for Particular Populations of Adolescents

Adolescents who have Run Away, are Homeless, or are Living on the Street

□ The formidable barriers to comprehensive health care for all adolescents are amplified for independent homeless youth. [...] When presenting at a traditional site such as a hospital emergency room, they are likely to be asked for a permanent address, health insurance information, and parental permission for treatment. Although some states consider these adolescents to be emancipated minors, confidentiality remains a key concern. Many such youth have been exploited and victimized by adults and are reluctant to trust health professionals and the traditional health-care system. Legal concerns regarding status or criminal offenses may lead to fear of police or social service agency notification. Affordability, denial of need, delay in seeking care, and lack of adequate follow-up, owing to the transient nature of the population, all complicate the management of health problems. ⁹³

Society for Adolescent Medicine

Adolescents in State Custody

☐ [Regarding service coordination and case management for children and adolescents in foster care who need mental health and substance abuse services] Information must be shared on a regular basis among organizations/agencies providing services/support to the child and/or their family. Every effort must be made to eliminate barriers, while complying with the confidentiality requirements in HIPAA. This information should follow the child from placement to placement. [...] [Regarding family participation in all aspects of planning, service delivery, and evaluation.] Family is defined (using the Federation of Families definition) as including biological, foster, and adoptive parents, grandparents and their partners, as well as kinship care givers and others who have primary responsibility for providing love, guidance, food, shelter, clothing, supervision, and protection for children and adolescents. It is important for the family to be actively invited as part of the engagement process at all levels of planning, service delivery, and evaluation: e.g., the system level, organizational level, and individual child level. 1,24

American Academy of Child & Adolescent Psychiatry and Child Welfare League of America, also endorsed by the American Academy of Pediatrics

☐ [Regarding HIV disease] Federal, state, juvenile, and local correctional facilities house significant numbers of individuals who are at risk for HIV disease. Voluntary testing, strict application of Universal Precautions and CDC guidelines, education/counseling services, protective devices availability and confidentiality are important areas for nurses working in these settings. [...] Testing for HIV disease is valid as a diagnostic tool. With advances in the diagnosis and treatment of HIV, it is important that those who are seropositive be identified early for the purposes of initiating early intervention. Accordingly, voluntary confidential testing with pre and post counseling for the purpose of initiating treatment should be available to persons who request it. Anyone with clinical indication of HIV disease and anyone who has engaged in high risk behaviors should be encouraged to test for HIV disease. While recent research has demonstrated that early treatment can delay the progression of the disease, it is not clear that large scale screening is efficacious and mandatory testing is not warranted. [...] HIV/AIDS education should be provided to all staff and inmates in jails, prisons, and juvenile confinement facilities. [...] Staff should also receive

American Nurses Association

Adolescents in State Custody

American Nurses Association (cont'd)

training on confidentiality as it relates to HIV disease. [...] It is important that the rules of confidentiality be followed in correctional institutions since labeling inmates as HIV positive places them at undue risk for compromised personal safety. The facility staff should keep informed of any changes related to confidentiality enacted by legislatures or determined by the courts as such information varies from state to state and from time to time. ⁶³

Society for Adolescent Medicine

□ [A]ccess to HIV testing and follow-up care [should be provided] to adolescents in juvenile detention or correctional facilities, foster care, or the mental health system. Specifically: they should be able to receive careful assessments, pre-test and post-test counseling, and confidential HIV testing if appropriate; they should be tested only with their voluntary informed consent; and the privacy of these young people should be protected to the maximum extent possible, although legal requirements applicable to youth in these systems may sometimes place limitations on the confidentiality of information, or on who makes decisions concerning disclosure. 92

Adolescents who are Gay, Lesbian, Bisexual, or Transgender

National Association of Pediatric Nurse Practitioners

As an organization that advocates for all children, NAPNAP affirms that all persons, regardless of gender-identity or sexual orientation, have the right to access quality health care resources. Many [gay, lesbian, bisexual, and transgender] GLBT adolescents and young adults are exposed to prejudice, resulting in stigma, hostility, and hatred which may hinder the ability of GLBT youth to achieve developmental tasks. GLBT youth have a higher level of isolation, runaway behavior, homelessness, domestic violence, depression, suicide, violent victimization, substance abuse, and school or job failure than heterosexual youth. Many individuals first become aware of their sexual orientation during adolescence, and may experience confusion. Health care providers may be failing to fully address issues of sexual orientation and confidentiality with adolescents.

In order to advocate for GLBT youth, NAPNAP asserts the following: [...] [Pediatric nurse practitioners] PNPs should maintain confidentiality regarding sexual orientation in accordance with state regulations pertaining to confidentiality with minors. ⁸²

Pregnant and Parenting Adolescents

American Public Health Association

□ [The American Public Health Association] [u]rges that services for pregnant adolescents include access to safe, legal, and confidential abortion counseling and services, as well as access to affordable, confidential prenatal and postpartum care and contraceptive services. ⁷¹

Policy Statements About Adolescents' Informed Consent and Confidential Access to Specific Health Care Services

Preventive Health Services

□ Ready access to adolescent preventive services is often limited by service-site location, scheduling difficulties, and concerns about confidentiality. [...] Confidentiality and consent issues may also limit access to care. From the adolescent's point of view, health care may not be sought if it is perceived that privacy may be breached in the process. Providers must be aware of the importance adolescents place on confidentiality, must have policies which respect adolescent privacy, and must make these policies clear to the adolescents and families who seek their services. Within confidential clinician-patient relationships, reimbursement is sometimes complicated and may require special flexibility. [...] The reimbursement procedures established by insurers and managed care providers should be designed so as not to breach the confidentiality expected by some adolescent patients. Preventive services for adolescents should be adolescent-friendly: comprehensive, confidential, respectful, developmentally appropriate, and interactive. ⁹⁰

Society for Adolescent Medicine

Dental Services

□ Attention should be given to the particular psychosocial aspects of adolescent dental care. Issues of consent, confidentiality, compliance, and others should be addressed in the care of these patients. ¹²

American Academy of Pediatric Dentistry

Contraception, Pregnancy-Related Services, Abortion, and Other Reproductive Health Services

□ Since the involvement of a concerned adult can contribute to the health and success of an adolescent, policies in health care settings should encourage and facilitate communication between a minor and her parent(s), when appropriate. However, concerns about confidentiality, as well as economic considerations, can be significant barriers to healthcare for some adolescents. For example, the potential health risks to adolescents if they are unable to obtain reproductive health services are so compelling that legal barriers and deference to parental involvement should not stand in the way of needed health care for patients who request confidentiality. ¹³

American Academy of
Pediatrics, also endorsed by
the American Academy of
Family Physicians, the
American College of
Obstetricians and
Gynecologists, and the
Society for Adolescent
Medicine

 $\hfill \Box$ b. Adolescents receiving contraceptive services should be accorded strict patient confidentiality. 8

American Academy of Family Physicians

□ Comprehensive health care of adolescents should include a sexual history that should be obtained in a safe, nonthreatening environment through open, honest, and nonjudgmental communication, with assurances of confidentiality. During the preadolescent years, the pediatrician can provide anticipatory guidance by discussing puberty and offering health education materials to the youth and family. With the onset of puberty, the patient's history should include information regarding attitudes and knowledge about sexual behavior, degree of involvement in sexual activity, and use of contraception. At the onset of puberty, private, confidential interviews with the adolescent should be part of a health maintenance visit.

American Academy of Pediatrics

The primary reason adolescents hesitate or delay obtaining family planning or contraceptive services is concern about confidentiality. 17

Contraception, Pregnancy-Related Services, Abortion, and Other Reproductive Health Services

American Academy of Pediatrics

☐ Pediatricians should integrate sexuality education into the confidential and longitudinal relationship they develop with children, adolescents, and families to complement the education children obtain at school and at home. [...] Unlike school-based instruction, discussion of sexuality with pediatricians provides opportunities for personalized information, for confidential screening of risk status, and for health promotion and counseling. Children and adolescents may ask questions, discuss potentially embarrassing experiences, or reveal highly personal information to their pediatricians. Families and children may obtain education together or in a separate but coordinated manner. Prevention and counseling can be targeted to the needs of youth who are and those who are not yet sexually active and to groups at high risk for early or unsafe sexual activity. Recommendations for pediatricians are as follows: [...] Provide sexuality education that respects confidentiality and acknowledges the individual patient's and family's issues and values. [...] Provide specific, confidential, culturally sensitive, and nonjudgmental counseling about key issues of sexuality. 28

American Academy of Pediatrics

☐ While waiting for the results of a urine pregnancy test, the pediatrician has the opportunity to discuss the adolescent's expectations and feelings about her possible pregnancy. The pediatrician should convey the results of the pregnancy test to the adolescent alone in a private setting. Minors have legal rights protecting their privacy about the diagnosis and treatment of pregnancy. Pediatricians should be familiar with local confidentiality laws being aware that they vary from state to state. In considering confidentiality, the pediatrician should assess the adolescent's ability to understand the diagnosis of pregnancy and appreciate the implications of that diagnosis. The diagnosis should not be conveyed to others, including parents, until the patient's consent is obtained, except when there are concerns about suicide, homicide, or abuse. [...] The pediatrician needs to be sensitive to family, social, and cultural issues that may influence the adolescent and her decisions about pregnancy. Adolescents should be encouraged to include their parents in a full discussion of their options. The pediatrician should explain how parental involvement can be helpful and that parents generally are supportive. If parental support is not possible, minors should be urged to seek the advice and counsel of adults in whom they have confidence, including other relatives, counselors, teachers, or clergy. This is especially true for younger adolescents, age 12 to 15 years. 18

American Academy of Pediatrics

1. Adolescents should be strongly encouraged to involve their parents and other trusted adults in decisions regarding pregnancy termination, and the majority of them voluntarily do so. A minor's decision to involve parents is determined by the quality of the family relationship, not by laws. Family communication is inherently a family responsibility, and parents themselves create the emotional atmosphere that fosters productive dialogue. Adolescents who feel loved and supported by their parents normally will communicate with them in times of crisis. Studies show that adolescents are most likely to disclose their pregnancies if the family has a history of warmth, rapport, and involvement of parents in past problem solving. As emphasized in previous AAP position statements, enhancing parental skills for listening, communicating, valuing, and nurturing throughout the childhood years is the most effective means of ensuring family involvement in adolescent

Contraception, Pregnancy-Related Services, Abortion, and Other Reproductive Health Services

decisions. The pediatrician's most valued role may be to strengthen these family communication skills and supportive behaviors. 2. Concerned professionals should make every effort to ensure that a pregnant teenager receives adult guidance and support when considering all the options available, so she can make the decision that is in her best interest. This is best achieved by adhering to existing professional ethics and standards for obtaining meaningful informed consent. Physicians should ensure that the minor patient has full information and has given careful consideration to the issues involved. They should encourage minors to consult with parents, other family members, or other trusted adults if parental support is not possible. The very young adolescent is especially needy in this regard. Ultimately, the pregnant patient's right to decide should be respected regarding who should be involved and what the outcome of the pregnancy will be, which is the approach most consistent with ethical, legal, and health care principles.

3. The AAP reaffirms its position that the rights of adolescents to confidential care when considering abortion should be protected. Genuine concern for the best interests of minors argues strongly against mandatory parental consent and notification laws. Although the stated intent of mandatory parental consent laws is to enhance family communication and parental responsibility, there is no supporting evidence that the laws have these effects. No evidence exists that legislation mandating parental involvement against the adolescent's wishes has any added benefit in improving productive family communication or affecting the outcome of the decision. There is evidence that such legislation may have an adverse impact on some families and that it increases the risk of medical and psychological harm to the adolescent. Judicial bypass provisions do not ameliorate the risk. 4. The AAP reaffirms its support of measures that increase access to health care for children and youths, regardless of age or financial status, and opposes unnecessary regulations that limit or delay access to care. The documented impact of parental consent laws is to reduce minors' access to early legal abortion. Public policies should encourage sexually active adolescents to seek timely, professional health care. The threat of compelled parental notification against the adolescent's wishes, even if judicial bypass is available, is a strong disincentive to seeking care. The AAP holds that public policies can and should encourage voluntary involvement of parents or other mature adults, but specific laws mandating notification of biological parents or legal guardians as a condition of service are counterproductive. 32

Adolescence is a time of psychosocial, cognitive, and physical development as young people make the transition from childhood to adulthood. This transition includes sexual development and often entails behaviors that put young women at risk for pregnancy and sexually transmitted diseases. Guidance from a physician, as well as needed reproductive health screening and care, can greatly facilitate young people's healthy transition to adulthood.

Health care professionals have an obligation to provide the best possible care to respond to the needs of their adolescent patients. This care should, at a minimum, include comprehensive reproductive health services, such as sexuality education, counseling, mental health assessment, diagnosis and treatment regarding pubertal development, access to contraceptives and abortion, pregnancy-related care, prenatal and delivery care, and diagnosis

American Academy of Pediatrics (cont'd)

American College of Obstetricians and Gynecologists Contraception, Pregnancy-Related Services, Abortion, and Other Reproductive Health Services

American College of Obstetricians and Gynecologists (cont'd) and treatment of sexually transmitted diseases. Every effort should be made to include male partners in such services and counseling.

Comprehensive services may be delivered to adolescents in a variety of sites, including schools, physician offices, and community-based and other health care facilities. Legal barriers that restrict the freedom of health care practitioners to provide these services should be removed. Institutional policies should be developed to require practitioners with views on confidentiality that restrict the provision of services to a minor to refer the patient to another practitioner.

Because the involvement of a concerned adult can contribute to the health and success of an adolescent, policies in health care settings should encourage and facilitate communication between a minor and her parent(s), when appropriate. However, concerns about confidentiality, as well as economic considerations, can be significant barriers to reproductive health care for some adolescents. The potential health risks to adolescents if they are unable to obtain reproductive health services are so compelling that legal barriers and deference to parental involvement should not stand in the way of needed health care for patients who request confidentiality. Therefore, laws and regulations that are unduly restrictive of adolescents' confidential access to reproductive health care should be revised. Institutional procedures that safeguard the rights of their adolescent patients, including confidentiality during initial and subsequent visits and in billing, should be established. ⁴³

American College of Physicians

☐ If a patient who is a minor requests termination of pregnancy, advice on contraception, or treatment of sexually transmitted diseases without a parent's knowledge, the physician may wish to attempt to persuade the patient of the benefits of having parents involved but should be aware that a conflict may exist between the legal duty to maintain confidentiality and the obligation toward parents or guardians. Information should not be provided to others without the patient's permission. In such cases, the physician should be guided by his or her conscience in light of the law. ⁴⁷

American College of Preventive Medicine

☐ [Regarding scope of reproductive health care benefits for adolescents enrolled in the State Children's Health Insurance Program] States should provide coverage for reproductive health assessment – with sexual history, behavioral risk assessment, and prevention counseling - during annual physical examination to all adolescents enrolled in SCHIP. [...] States should provide coverage for family planning services and counseling, including pregnancy testing; pregnancy option counseling; prenatal, obstetric, and postpartum care; distribution of contraceptive devices and birth control methods; available emergency contraception; and medical and surgical abortions as needed and permitted by law, to all sexually active adolescents enrolled in SCHIP. [...] States should provide for confidential reproductive health care services and information to all adolescents enrolled in SCHIP. There is an important link between adolescents' perception of confidentiality and use of health care services and information. Because adolescents' health risks lie largely in potential risks from health-related behaviors, confidentiality in health care may be one of the most important factors that affect adolescents' decision to disclose and discuss risky behaviors, and ultimately to seek and use health care services. 49

- Our AMA continues to oppose regulations that require parental notification when prescription contraceptives are provided to minors through federally funded programs, since they create a breach of confidentiality in the physician-patient relationship. The Association encourages physicians to provide comparable services on a confidential basis where legally permissible. ⁵⁶
- American Medical Association

☐ Physicians should ascertain the law in their state on parental involvement to ensure that their procedures are consistent with their legal obligations. Physicians should strongly encourage minors to discuss their pregnancy with their parents. Physicians should explain how parental involvement can be helpful and that parents are generally very understanding and supportive. If a minor expresses concerns about parental involvement, the physician should ensure that the minor's reluctance is not based on any misperceptions about the likely consequences of parental involvement. Physicians should not feel or be compelled to require minors to involve their parents before deciding whether to undergo an abortion. The patient, even an adolescent, generally must decide whether, on balance, parental involvement is advisable. Accordingly, minors should ultimately be allowed to decide whether parental involvement is appropriate. Physicians should explain under what circumstances (e.g., life-threatening emergency) the minor's confidentiality will need to be abrogated. Physicians should try to ensure that minor patients have made an informed decision after giving careful consideration to the issues involved. They should encourage their minor patients to consult alternative sources if parents are not going to be involved in the abortion decision. Minors should be urged to seek the advice and counsel of those adults in whom they have confidence, including professional counselors, relatives, friends, teachers, or the clergy. 55

American Medical Association

☐ The American Public Health Association, [n]oting that adolescents tend not to seek contraception or reproductive health care until after they have initiated sexual intercourse; and [n]oting that sexually active and/or pregnant adolescents need informed, professional counseling and health care regardless of whether they wish to prevent, continue, or terminate a pregnancy; and [u]nderstanding that while parental involvement in minors' decisions may be very helpful, it can also be punitive, coercive and/or abusive; and [n]oting that physicians and other health care professionals have the obligation to provide care that is in the best interest of that patient; and [e]mphasizing that the threat of compelled parental notification is a strong disincentive to an adolescent's seeking professional reproductive health care or advice; and [n]oting that parental involvement laws, whether notification or consent, for adolescent reproductive health care (including contraception, prenatal care, delivery services, postpartum care, or abortion), do not appreciably discourage adolescent sexual activity; and [f]urther noting that adolescents are particularly vulnerable to misinformation, scare tactics, and other propaganda; and [n]oting that safe abortion is a component of comprehensive reproductive health care; therefore 1. [u]rges that public policies and laws concerning adolescent access to reproductive health care, adolescent pregnancy and pregnancy outcome be designed for the primary purposes of preventing unintended pregnancy and providing sensitive, competent, professional health care to all adolescents; 2. [u]rges that such

American Public Health Association

American Public Health Association (cont'd)

policies reflect the reality of adolescent sexual activity and take into consideration the demonstrably negative effect of compelled parental involvement on some adolescents' contraceptive behavior; 3. [u]rges that adequate and proper care for pregnant adolescents includes encouragement to involve a mature adult in decision-making about pregnancy outcome, provided that such involvement is not dictated or compelled; 4. [u]rges that services for pregnant adolescents include access to safe, legal, and confidential abortion counseling and services, as well as access to affordable, confidential prenatal and postpartum care and contraceptive services; and 5. [u]rges that a national policy on reproductive health care for adolescents include: a) Comprehensive health and sexuality education in schools extending from kindergarten through high school; b) Confidential health services tailored to the needs of adolescents, including sexually active adolescents, adolescents considering sexual intercourse, and those seeking information, counseling, or services related to preventing, continuing, or terminating a pregnancy; c) Public policies that encourage sexually active and pregnant adolescents to seek professional health care. These policies can encourage mature adult involvement (including parental involvement) but should in no way dictate or compel the specific involvement of parents or guardians in adolescent decisions regarding their reproductive health. 71

American Public Health Association

The American Public Health Association [...] [n]oting that many state restrictions on abortion clinics, where 90 percent of abortions are performed, deny access to abortion services, especially for women in rural areas and for teenagers; and [n]oting that one out of 10 women aged 15 to 19 becomes pregnant each year in the United States and that five out of six such pregnancies are unintended, and also that the United States has a much higher rate of teenage pregnancy than six other Western countries which reflects the lack of adequate family resources and education; and [n]oting further that state efforts to compel rather than to encourage parental notification of teenagers' abortions serve only to delay and deter access of pregnant teenagers to abortion services and violate their constitutional right of privacy; therefore 1. [r]eaffirms its long-standing commitment to the fundamental legal right of women to choose abortion; to accessible, affordable, and safe abortion services for all women who need and choose them. ⁷⁵

American Public Health Association

□ The American Public Health Association, [n]oting that 458,000 women in the United States under the age of 18 unintentionally become pregnant each year and that unintended early teenage pregnancy generally has negative consequences for the health and welfare of the adolescent woman, her child (if she gives birth) and her family, and the society as a whole; and [n]oting that although approximately 600,000 women under age 18 obtain contraception (usually oral contraceptives) at organized family planning clinics and 500,000 are estimated to do so from private physicians, most of the remaining 1.3 million of the 2.4 million women under age 18 who are sexually active and able to get pregnant but do not want to do so during a year are at very high risk of becoming pregnant because they are using contraceptive methods with high failure rates or no contraception at all; and [n]oting that fear of parental knowledge is a major reason adolescents delay coming to a

family planning clinic for about 12 months after they become sexually active, and that 21 percent of the unmarried minors obtaining prescription contraceptives at family planning clinics would use less effective nonprescription contraception (including withdrawal and rhythm) or no method at all if parental notification were required; and [n]oting that minors obtaining family planning services from organized clinics receive preventive health screening (Pap smears, breast examinations, blood pressure checks, etc.) as well as the opportunity for screening for sexually transmitted diseases; and [n]oting that most family planning agencies attempt to encourage adolescent clients to voluntarily involve their parents in decisions related to their sexual activity and contraceptive use through a variety of activities; and [n]oting that the American Public Health Association has urged "that contraceptive services be made available to minors in a confidential, nonjudgmental atmosphere, and that efforts be made to clarify or change laws regarding parental consent in those states where the legality of providing such services without parental consent is now in doubt;" [...] 1. [c]ommends the actions of family planning providers to encourage and help adolescent clients involve their parents in decisions related to sexual activity and contraceptive use; 2. [a]dvocates that providers encourage, but not mandate, such involvement; 3. [s]trongly opposes policies requiring parental consent or notification as a qualification of minors for initial or continued receipt of prescription contraceptives. 73

American Public Health
Association (cont'd)

☐ The American Public Health Association, [n]oting that it has been longstanding policy to support the provision of services to all those who voluntarily desire to control their fertility; and [n]oting that for various reasons these services tend to be less accessible to adolescents than adults; and [n]oting that male and female adolescents have a right to full and adequate knowledge that can enable them to make responsible choices about their own sexuality and fertility; [...] 1. Recommends that ways be sought to ensure that the following provisions be included in federal, state, or local legislation and programs dealing with adolescent health and childbearing; a. Adolescent sexuality and prevention of undesired pregnancy be given a high priority, including making available pertinent information about sexuality and reproduction, and provision of contraceptive services on a convenient, dignified and confidential basis to all young men and women who need and want them; b. Early pregnancy diagnostic services be made readily available and, if the pregnancy is confirmed, supportive pregnancy counseling and unbiased information about all the options available, including abortion, be provided; c. Certain essential services be provided for young men and women who, on the basis of free and informed choice, decide to carry a pregnancy to term, with special attention to be given to those in their early teens for whom the social, psychological, and health risks are the greatest; d. In addition to the usual health services, other short- and long-term services should be provided which help young parents to complete their education and to become economically self- sufficient after the birth of their child. e. Provision of human sexuality education, as well as family planning information and services, be required of all relevant public programs. 74

American Public Health Association

American Public Health Association

□ The American Public Health Association, [r]eaffirming that the American Public Health Association holds that the ability to control one's own fertility is a fundamental right and a necessity for health; and [...] [r]ecognizing that many minors cannot obtain contraceptive services due to lack of confidentiality or to providers' concerns over the legality of providing such services without parental consent; [...] 3. [u]rges that contraceptive services be made available to minors in a confidential, nonjudgmental atmosphere, and that efforts be made to clarify or change laws regarding parental consent in those states where the legality of providing such services without parental consent is now in doubt. ⁷⁰

Society for Adolescent Medicine

☐ The Society for Adolescent Medicine hereby resolves that contraceptive education, counseling, and services should be made available to all male and female adolescents desiring such care on the adolescents' own consent without legal or financial barriers. Parental involvement should be encouraged, but this should not be required through either consent or notification. [...] The Society for Adolescent Medicine hereby resolves that pregnancy detection and subsequent prenatal care, counseling, educational, and postnatal services (including child care) should be available and accessible to adolescents who choose to continue their pregnancies, without legal or financial barriers; that services should be available to the adolescent's partner and family, if she desires, and should include counseling on adoption and/or parenting. Services should be available on a confidential basis. [...] The Society for Adolescent Medicine hereby resolves that although prevention of unwanted pregnancy is the highest priority, adolescents (whether indigent or well-to-do) must have access to counseling about all options and access to elective termination of pregnancy as a legal, safe, available alternative to continuing a pregnancy; that the adolescent should have access to abortion without legal or financial barriers and without interference from anti-abortion demonstrations; and that the decision to terminate a pregnancy should rest with the pregnant adolescent in concert with the advice and counsel of her physician. Although involvement of significant others should be strongly encouraged, particularly for minors, mandatory parental consent and/or notification should not be required. When determination of maturity is necessary, that determination is best made by a knowledgeable health professional. [...] The Society for Adolescent Medicine hereby resolves that adolescents should have access to education, counseling, and health care services for the prevention, screening, diagnosis, and treatment of sexually transmitted diseases; and that minors should have access to these services on their own consent. 95

Testing and Treatment for HIV and Sexually Transmitted Infections

American Academy of Child & Adolescent Psychiatry

□ All HIV antibody testing must be done with informed consent. It is not enough just to have a consent form signed but it must be document[ed] that the person authorizing testing is fully informed of the consequences of both a positive or negative result. There are specific laws regarding confidentiality of HIV antibody testing results and who authorizes consent in minors. These laws vary form state to state. Prior to obtaining consent, ensure the laws are understood. Results of patients' HIV antibody tests will be maintained in a confidential manner. A patient's HIV status should be shared only with those

staff who need to know the status to appropriately care for the child while an inpatient. Sharing of HIV status should, of course, be in compliance with applicable state and federal law. 6

Laws concerning consent and confidentiality for HIV care and treatment vary from state to state, and pediatricians need to be familiar with the laws of the state in which they practice. [...] Some adolescents may not wish to involve a parent in decisions relative to evaluation or treatment of HIV infection. Such reluctance may arise from a desire not to inform family members about HIV status or reluctance to reveal behaviors that placed the adolescent at risk for infection. Although it is usually best to involve the family in the health care of adolescents, this is not always the case. Deference to parental wishes to be informed must not interfere with needed evaluation or treatment of adolescents. For adolescents who are able to understand the implications of testing and treatment and are capable of informed consent, and in the absence of local laws to the contrary, it is best to proceed on the basis of this consent alone rather than insisting on parental involvement. Similarly, an adolescent's consent should be obtained before release of any information concerning HIV status.

Generally, pediatricians should respect an adolescent's request for privacy. Nevertheless, questions about whether pediatricians may disclose or receive information about a patient's HIV status without the consent of the patient can arise in several contexts, including disclosure by obstetricians to pediatricians, mandated reporting to health departments, reporting to institutional authorities and employers, the care of accused or convicted sex offenders, instances of accidental needle sticks involving known HIV-infected patients, and issues of charting HIV status in the medical record. Although each of these contexts may at times involve an adolescent patient, they are not specific to young people. Accordingly, disclosure of the HIV status of an adolescent should be held to the same legal and ethical standards as disclosure of the HIV status of an adult. A concern most relevant to the care of HIV-infected adolescents is the limits of confidentiality as they would apply to sexual partners. A difficult question is whether to disclose HIV status to the sexual partner(s) of a patient known to be HIV positive and who persistently refuses to agree to such disclosure. There should be little debate about the desirability of using all reasonable means to persuade an infected person to inform his or her partner(s) on a voluntary basis. Physicians who intend to disclose information about HIV infection status to sexual partners should consider their duty to inform adolescent patients before testing that results will be disclosed to partners and under what circumstances. Partner notification (without revealing the source of exposure) is available in many areas through local health departments. Maintaining confidentiality is important. Disclosure of HIV infection status is regulated by state laws. Disclosure of HIV infection status to school authorities without an adolescent's consent generally is not indicated. When desired by an adolescent, pediatricians can play an important role in disclosure and education of school authorities. [...]

3. Availability of HIV testing should be discussed with all adolescents and should be encouraged with consent for those who are sexually active or substance users. 4. Although parental involvement in adolescent health

American Academy of Child & Adolescent Psychiatry (cont'd)

American Academy of Pediatrics

American Academy of Pediatrics (cont'd)

care is a desirable goal, consent of an adolescent alone should be sufficient to provide evaluation and treatment for suspected or confirmed HIV infection. ¹⁴

American Academy of Pediatrics

□ Disclosure of HIV infection status to children and adolescents should take into consideration their age, psychosocial maturity, the complexity of family dynamics, and the clinical context. [...] For adolescents, the American Academy of Pediatrics has established that health care professionals have an ethical obligation to provide counseling to respond to the needs of adolescent patients and to insure that adolescents have an opportunity for examinations and counseling apart from their parents. Consequently, physicians should provide full disclosure of HIV status to their adolescent patients. [...] Adolescents should know their HIV status. They should be fully informed to appreciate consequences for many aspects of their health, including sexual behavior. Adolescents also should be informed of their HIV status to make appropriate decisions about treatment and participation in clinical treatment trials. Physicians should also encourage adolescents to involve their parents in their care. ¹⁹

American College of Obstetricians and Gynecologists □ Confidentiality concerns limit the use of medical care by adolescents. Adolescents are more willing to communicate with and seek health care from physicians who assure confidentiality. [...] Physicians are encouraged to establish office policies regarding confidential care for adolescents and clearly communicate these policies to adolescents and their parents. Although providing confidentiality to adult patients is relatively easy, parental consent and billing issues for the treatment of adolescents can make confidentiality for adolescents a much more complex task. [...] Physicians providing care for an adolescent population should be familiar with current state statutes on the rights of minors to consent to health care services, as well as those laws that affect confidentiality. Providers should encourage and, when appropriate, facilitate communication between a minor and her parent(s). ⁴⁵

American College of Preventive Medicine □ Most sexually active adolescents would agree only to confidential STD testing. Many health care facilities, however, require the consent of parents or spouses, or may be forbidden by law to provide services to adolescents. Sexually active adolescents who refuse STD testing because of privacy concerns place themselves at risk of complications from undiagnosed infections, and limit the potential of screening programs to reduce STD rates. ⁴⁹

American Medical Association

□ The AMA urges state and local medical societies to work with their respective health departments and communities to develop and support appropriate legislation to decrease the spread of sexually transmitted diseases (STDs) in minors, specifically by allowing minors to consent for the means of prevention, diagnosis and treatment of STDs, including AIDS. ⁶¹

American Medical Association

□ Our AMA (1) supports continued action to assert appropriate leadership in a concerted program to control venereal disease; (2) urges physicians to take all appropriate measures to reverse the rise in venereal disease and bring it under control; (3) encourages constituent and component societies to support and initiate efforts to gain public support for increased appropriations for public health departments to fund research in development of practical

methods for prevention and detection of venereal disease, with particular emphasis on control of gonorrhea; and (4) in those states where state consent laws have not been modified, encourages the constituent associations to support enactment of statutes that permit physicians and their co-workers to treat and search for venereal disease in minors legally without the necessity of obtaining parental consent. ⁵⁴

American Medical Association (cont'd)

☐ [Regarding HIV disease] Federal, state, juvenile, and local correctional facilities house significant numbers of individuals who are at risk for HIV disease. Voluntary testing, strict application of Universal Precautions and CDC guidelines, education/counseling services, protective devices availability and confidentiality are important areas for nurses working in these settings. [...] Testing for HIV disease is valid as a diagnostic tool. With advances in the diagnosis and treatment of HIV, it is important that those who are seropositive be identified early for the purposes of initiating early intervention. Accordingly, voluntary confidential testing with pre and post counseling for the purpose of initiating treatment should be available to persons who request it. Anyone with clinical indication of HIV disease and anyone who has engaged in high risk behaviors should be encouraged to test for HIV disease. While recent research has demonstrated that early treatment can delay the progression of the disease, it is not clear that large scale screening is efficacious and mandatory testing is not warranted. [...] HIV/AIDS education should be provided to all staff and inmates in jails, prisons, and juvenile confinement facilities. [...] Staff should also receive training on confidentiality as it relates to HIV disease. [...] It is important that the rules of confidentiality be followed in correctional institutions since labeling inmates as HIV positive places them at undue risk for compromised personal safety. The facility staff should keep informed of any changes related to confidentiality enacted by legislatures or determined by the courts as such information varies from state to state and from time to time. 63

American Nurses Association

□ 1. Psychiatrists who work with adolescents have a responsibility to educate themselves and consider consultation as needed with regard to medical, psychosocial, ethical, and legal aspects of HIV infection particularly as they relate to youth. […]

American Psychiatric Association

- 4. When adolescents live in families, these relationships significantly influence adolescent behavior. Thus, culturally competent family assessment needs to be a central part of the evaluation process, and education must be directed to these families as well as adolescents. [...]
- 6. In areas of HIV testing, sexual activity, reproductive planning, contraception, and access to medical treatment, psychiatrists should be familiar with state and local statutes regarding minor consent, age and criteria for emancipation, limits of confidentiality, notification requirements, and rights in emergent medical and psychosocial situations (e.g. acute general mental status changes or sexual trauma). ⁶⁷
- □ NASP recommends that only those who have a legitimate need to know be informed regarding a child's HIV status. In some cases, this may mean that classroom teachers and school psychologists will not have access to this information unless it can be documented that such disclosure will benefit the

National Association of School Psychologists

National Association of School Psychologists (cont'd)

child and a parent has consented to its dissemination. [...] Regardless of individual decisions regarding disclosure, school personnel must be fully prepared to handle the rapid spread of HIV-related rumors among students and staff. 83

Society for Adolescent Medicine ☐ The Society for Adolescent Medicine believes that [...] there should be no mandatory of testing of adolescents. Confidential testing should be readily available to adolescents and every effort should be made to ensure the rights of privacy of the patient. Anonymous testing should also be available for those who so choose. Programs and the clients they serve should be made aware of the positive and negative features of each approach to testing. Counseling should be developmentally and culturally sensitive and always identify risks as well as benefits of testing. Both counseling and testing should take place in settings in which adolescents feel comfortable and where care and support services can be made readily available. Appropriate parental or other adult support should be incorporated into the process whenever possible. [...] With regard to counseling and testing services for adolescents, we make the following recommendations: [...] a) there should be no mandatory HIV testing of individual adolescents or population groups as a prerequisite for admission to programs, services, or placements; b) there should be no involuntary routine HIV testing for adolescents; c) an adolescent should not be tested for HIV without consent; informed consent should be obtained from the adolescent if the adolescent is capable of consenting or, if the adolescent is not capable of giving consent, consent should be obtained from some other person with appropriate legal authority or from a court. [...] [W]hen indicated, conduct HIV testing based on clinical criteria or an appropriate request of an adolescent, in settings where pretest and post-test counseling that is sensitive, age-appropriate, and culturally appropriate is available. Confidential testing is preferred because it more readily allows the immediate provision of medical and support services to be offered to the adolescent. However, anonymous HIV testing services should also be available for the adolescent who prefers to be tested in this manner. This modality of testing is often preferred by older or emancipated adolescents. If anonymous testing is provided, efforts need to be made prior to offering these services to a particular adolescent to ascertain if he/she will be responsible in returning for results and if an appropriate support mechanism is in place to help them cope with a positive test result. Whether the testing is confidential or anonymous, special preparations should be made, including training of staff, to ensure that services are appropriate to the adolescent age group. [...]

[S]trictly maintain the confidentiality of an adolescent's HIV test results and other HIV-related information. [S]hare HIV-related information about an adolescent among health care professionals and other services providers only with appropriate authorization. The following guidelines should be adopted: a) test results should only be released with the explicit agreement, preferably in writing, of the adolescent if the adolescent has consented to the test; or b) in those extraordinary instances when an adolescent has not consented to the test, authorization to release the test results should be obtained from someone with proper legal authority to do so as directed by order of the court. ⁹²

Mental Health and Substance Abuse Services

□ Patients requiring treatment for mental illnesses are less likely to seek help and more likely to drop out of treatment for fear their records will be disclosed. This is particularly true of parents seeking help for their children. If a child's medical record does not have long-term privacy protections, information regarding diagnosis and treatment can lead to discrimination throughout his or her life. [...] Trust is the essential imperative in the doctorpatient relationship. This is particularly true between a child and adolescent psychiatrist and a child or adolescent patient and his or her family. Too often parents are apprehensive about taking their child to see a child and adolescent psychiatrist. The possibility that their child's medical information could be disclosed, makes it less likely that parents will chose to seek treatment. ⁴

American Academy of Child & Adolescent Psychiatry

□ The Academy encourages the child and adolescent psychiatrist to carefully consider the use of drug and alcohol screening tests for the evaluation and treatment of [children and adolescents who may have coexisting psychiatric and substance abuse disorders]. Whether or not laboratory testing occurs depends on the careful judgment of the physician. [...] The child and adolescent psychiatrist should be knowledgeable about the following procedures of blood and drug testing: [p]roper collection, labeling, storage, and transfer of specimens; [p]roper record keeping and communicating of results from the laboratory; [t]he protection of the confidentiality of results; [t]he reliability and validity of the variety of tests; [and] [t]he appropriate interpretation of the testing results within the context of a comprehensive biopsychosocial evaluation. [...]

American Academy of Child & Adolescent Psychiatry

When assessing informed consent and confidentiality issues with substance abusing children and adolescents, the psychiatrist must try to answer the following questions: Is it the child or the parents who are asking for help? Is there a positive treatment alliance with the child and/or with the parents? Are the parents allied with their child's best interests regarding assessment, drug and alcohol screening, and treatment? Is the patient generally acting with poor judgment? Is the patient's behavior dangerous and life-threatening enough to break confidentiality?

Whether or not the psychiatrist obtains informed consent from the patient for drug testing or breaks confidentiality about the results with the patient is a difficult judgment which must include the following factors. Some substance abus[ing] teenagers sincerely ask for confidential help while others continue to use chemicals and to resist help, even when they regularly attend treatment sessions. The parents may be more motivated for treatment than the patient or vice-versa. The treatment alliance with an actively substance abusing adolescent can be non-existent in spite of lengthy treatment attempts. A patient can hide his or her suicidal thoughts and substance use from the clinician and assume a mask of good health. [...]

The child and adolescent patient should be given the right of informed consent about drug and alcohol testing. This fosters a positive alliance with the patient. It may be appropriate, however, to obtain informed consent for testing from the parents alone, when the minor patient exhibits poor judgment, cannot make a positive treatment alliance, is dangerous to him or herself or to others, does not show concern for his or her condition, and/or refuses help. [...]

Mental Health and Substance Abuse Services

American Academy of Child & Adolescent Psychiatry (cont'd)

Respecting the confidentiality of a child or adolescent is routine, but this may be more difficult when the problem is substance abuse. Confidentiality is not unconditional when a child's mental status is impaired. In these cases, when the child or adolescent is judged to be in a life-threatening situation, the clinician may find it medically necessary to take responsibility to protect the patient's health instead of the confidentiality and to share the test results with the parents. ⁵

American Academy of Pediatrics

□ Although confidentiality is important in adolescent health care, for adolescents at risk to themselves or others, confidentiality must be breached. Pediatricians need to inform the appropriate persons when they believe an adolescent is at risk of suicide. [...] In addition to an in-depth psychological evaluation of the adolescent, family members should be interviewed to obtain additional information to help explain the adolescent's suicidal thoughts or attempt. This information includes detailed questions about the adolescent's medical, emotional, social, and family history with special attention to signs and symptoms of depression, stress, and substance abuse. With parental permission and adolescent assent, teachers and family friends also may provide useful information if confidentiality is not breached. ³⁰

American Academy of Pediatrics

☐ The American Academy of Pediatrics (AAP) recognizes the abuse of psychoactive drugs as one of the greatest problems facing children and adolescents and condemns all such use. Diagnostic testing for drugs of abuse is frequently an integral part of the pediatrician's evaluation and management of those suspected of such use. "Voluntary screening" is the term applied to many mass non-suspicion-based screening programs, yet such programs may not be truly voluntary as there are often negative consequences for those who choose not to take part. Participation in such programs should not be a prerequisite to participation in school activities. Involuntary testing is not appropriate in adolescents with decisional capacity - even with parental consent—and should be performed only if there are strong medical or legal reasons to do so. The AAP reaffirms its position that the appropriate response to the suspicion of drug abuse in a young person is the referral to a qualified health care professional for comprehensive evaluation. [...] The AAP does not object to diagnostic testing for the purpose of drug abuse treatment. Testing should be approached in a fashion similar to diagnostic testing for other diseases, which includes obtaining informed consent from individuals with decisional capacity. Involuntary testing would be justified only if the adolescent were at risk of serious harm that could be averted only if the specific drug were identified. If the treatment and therapy would not be changed by testing, involuntary testing would not be justified. [...] Because serious legal consequences may result from a positive drug screen, it is a minimal requirement that there be candid discussion regarding confidentiality and the need for informed consent from a competent individual. If confidentiality issues are adequately addressed, a competent adolescent may consent to testing and counseling without the knowledge of parents, police, or school administrators. [...] Screening or testing under any circumstances is improper if clinicians cannot be reasonably certain that the laboratory results are valid and that patient confidentiality is assured. 31

Mental Health and Substance Abuse Services

- □ Appropriate interviewing techniques are critical in obtaining a comprehensive substance abuse history. Central to this is the issue of confidentiality, and the most useful information will be obtained in an atmosphere of mutual trust and comfort. Pre-teens as well as teenagers should be interviewed privately during each office visit with the reassurance of confidentiality and a discussion of its limits. [...] Guidelines published by the American Academy of Pediatrics as well as issues of consent and confidentiality should be considered when deciding whether to use drug testing in the diagnosis and management of substance abuse. [...] Pediatricians should: [...] interview the adolescent alone to obtain a meaningful history of drug use and/or associated problems and to assure confidentiality, except when a threat of harm to self or others exists or when reporting is required by law. [...] Patient consent should generally be obtained before testing for drugs of abuse, but may be waived when the patient's mental status or judgment is impaired. ³³
- □ Pediatricians must be familiar with state and federal regulations governing confidential exchange of information about substance abuse treatment. These are available from the state alcohol and substance abuse treatment regulatory agencies. ²²
- □ [Regarding drug education and testing of collegiate student athletes] A drug education program (with or without testing) should reflect the institution's overall commitment to eliminating drug abuse among its students, faculty, and staff. [...] No institution should initiate a drug testing component without the advice of legal counsel. The structure of this component should reflect consideration of the rights of the individual student, as well as concern for the goals of the institution. The component should provide for informed consent in advance by all students required to participate, and for due process in the event of the imposition of sanctions for alleged violations. [...] The institution should guarantee that the test results and any related records will be handled in a strictly confidential manner, in accordance with established university procedures. Further, test data should be included in medical or counseling records only, not in athletic or academic records. ³⁶

American Academy of Pediatrics

American Academy of Pediatrics

American College Health Association

Policy Statements About Confidentiality in Particular Health Care Settings

Schools and School Health Centers

American Academy of Child & Adolescent Psychiatry

□ [T]he Academy recommends that in communities where the need for such services is indicated, school systems should collaborate with local health agencies to establish health care clinics which would provide a full range of services including counseling and information regarding reproductive health. Where health services are provided to adolescents, these services should maintain the traditional practices regarding patient confidentiality. ²

American Academy of Pediatrics

☐ Adolescents, for a variety of reasons (e.g., emancipation, independence, desire for confidentiality), often will not seek out or take advantage of services in traditional settings. [...] Expanded school health services carry inherent and unique issues of patient confidentiality, consent, compliance, and continuity that need different solutions than they would in traditional health care settings and in schools without expanded health services. [...] Parents should be encouraged to be primarily and intimately involved in the health education and health supervision of their children. Issues of medical liability and confidentiality should be identified and addressed during a registration process. Typically, a standard parent permission form is prepared as a component of registration for the school-based clinic so that students may receive services. At the very least, this should include permission for the school health center to exchange information with the primary care provider and with the school's traditional health staff (e.g., school nurse, school counselor) for matters that pertain to a child's well-being at school. If the school's plan includes provisions for adolescents to receive services without parent notification or health plan billing, this too must be addressed at the time of registration. 27

American Academy of Pediatrics

☐ School policies and practices for medication administration must ensure that student confidentiality is protected, as outlined in the Family Education Rights and Privacy Act and the Health Insurance Portability and Accountability Act. ²¹

American Academy of Pediatrics

[Regarding school health assessments] Each child should be examined individually (rather than in groups) to ensure adequate attention to individual problems and concerns and to protect confidentiality and the child's sense of modesty. Parents should consent to the school health evaluation and be present, particularly in the primary grades. ²⁶

American Medical Association

 $f \Box$ Before patient services begin, policies on confidentiality should be established with the advice of expert legal advisors and the school health council. 60

Statement of the National Task Force on Confidential Student Health Information, a project of and endorsed by the American School Health Association □ The National Task Force [on Confidential Student Health Information] recommends that all school personnel regard as confidential all information related to a specific student's physical, mental, and developmental health status, whether that information is written, oral, or in electronic form. This information is subject to the protections required by federal and state law and the local school district's confidentiality policies and practices. School districts have a responsibility to ensure that a specific student's health information is maintained, stored, retrieved, and transferred in ways that protect students' and their family's privacy. This responsibility includes adopting specific policies, developing clear administrative procedures that protect confidential

Statement of the National Task

Force on Confidential Student

Health Information, a project of and endorsed by the

American School Health

Association (cont'd)

Schools and School Health Centers

student health information, identifying sanctions and penalties when rules are violated, and providing staff training that addresses uniform implementation of the policies and procedures.

Clear policies and procedures help school health professionals balance the need to protect confidentiality with the need to provide relevant information to other school personnel in order to provide students with appropriate educational programs and a safe environment. [...]

Recommended guidelines for protecting confidential student health information: [1] Distinguish student health information from other types of school records; [2] Extend to school health records the same protections granted medical records by federal and state law; [3] Establish uniform standards for collecting and recording student health information; [4] Establish district policies and standard procedures for protecting confidentiality during the creation, storage, transfer, and destruction of student health records; [5] Require written, informed consent from the parent and, when appropriate, the student, to release medical and psychiatric diagnoses to other school personnel; [6] Limit the disclosure of confidential health information within the school to information necessary to benefit students' health or education; [7] Establish policies and standard procedures for requesting needed health information from outside sources and for releasing confidential health information, with parental consent, to outside agencies and individuals; and [8] Provide regular, periodic training for all new school staff, contracted service providers, substitute teachers, and school volunteers concerning the district's policies and procedures for protecting confidentiality. 76

- National Assembly on School-Based Health Care
- appropriate participation in decisions regarding health care and prevention activities. Involv[e] the parents or other adult caregivers as supportive participants in the student's health care whenever appropriate and possible. Ensur[e] the confidentiality of information, whether transmitted through conversation, billing activity, telemedicine, or release of medical records. Provid[e] services and materials that are culturally sensitive and respectful of family values and diversity. ⁷⁸

☐ [School based health services should]: Encourag[e] the student's active, age

- National Assembly on School-Based Health Care
- □ Collaboration between health care providers in [school based health centers] SBHCs and school nurses enhances students' health, academic outcomes, lifelong achievement, and over-all student and staff well-being. In support of successful school nurse-school-based health center partnerships, it is our shared vision that collaboration should be characterized by: inclusion of student, family, and school staff within the parameters of confidentiality; [...] joint policies and procedures that ensure the quality and confidentiality of care received by students; [and] information sharing and exchange that protects student privacy and ensures continuity and coordination of care. ⁸⁰
- National Assembly on School-Based Health Care
- ☐ School-based health centers [should] have a policy on parental consent. ⁷⁷

Schools and School Health Centers

National Association of School Psychologists

School psychologists respect the confidentiality of information obtained during their professional work. Information is revealed only with the informed consent of the child, or the child's parent or legal guardian, except in those situations in which failure to release information would result in clear danger to the child or others. Obsolete confidential information will be shredded or otherwise destroyed before placement in recycling bins or trash receptacles.

School psychologists discuss confidential information only for professional purposes and only with persons who have a legitimate need to know. School psychologists inform children and other clients of the limits of confidentiality at the outset of establishing a professional relationship. [...]

School psychologists recognize the importance of parental support and seek to obtain that support by assuring that there is direct parent contact prior to seeing the child on an on-going basis. (Emergencies and "drop-in" self-referrals will require parental notification as soon as possible. The age and circumstances under which children may seek services without parental consent varies greatly; [school psychologists should] be certain to [...] "adhere to federal, state, and local laws and ordinances governing their practice and advocacy efforts. If regulations conflict with ethical guidelines, school psychologists seek to resolve such conflict through positive, respected, and legal channels, including advocacy efforts involving public policy.") School psychologists secure continuing parental involvement by a frank and prompt reporting to the parent of findings and progress that conforms to the limits of previously determined confidentiality.

School psychologists encourage and promote parental participation in designing services provided to their children. When appropriate, this includes linking interventions between the school and the home, tailoring parental involvement to the skills of the family, and helping parents gain the skills needed to help their children. School psychologists respect the wishes of parents who object to school psychological services and attempt to guide parents to alternative community resources. [...]

School psychologists discuss the rights of parents and children regarding creation, modification, storage, and disposal of confidential materials that will result from the provision of school psychological services. [...]

School psychologists ascertain that information about children and other clients reaches only authorized persons. [...] School psychologists assist agency recipients to establish procedures to properly safeguard confidential material. [...]

School psychologists comply with all laws, regulations and policies pertaining to the adequate storage and disposal of records to maintain appropriate confidentiality of information. [...] School psychologists maintain full responsibility for any technological services used. All ethical and legal principles regarding confidentiality, privacy, and responsibility for decisions apply to the school psychologist and cannot be transferred to equipment, software companies, or data processing departments. [...] To ensure confidentiality, student/client records are not transmitted electronically without a guarantee of privacy. In line with this principle, a receiving FAX machine must be in a secure location and operated by employees cleared to

Schools and School Health Centers

work with confidential files, and e-mail messages must be encrypted or else stripped of all information that identifies the student/client. ⁸⁴

□ Social workers in schools must [...] recognize that although the student is the identified client, the parents of a student younger than age 18 have certain rights, unless the student is an emancipated minor. This presents social workers in schools with a dual client situation, which can be especially complex if the student is pregnant and chooses not to inform her parents. Social workers must be familiar with federal and state laws as well as the local education agency's policies and procedures for reporting child abuse and neglect and laws of confidentiality regarding HIV/AIDS and drugs and alcohol. School social workers are bound by a duty to warn if there is a danger to the student or another individual. 87

National Association of School Psychologists (cont'd)

National Association of Social Workers

College Health Service

☐ Students have a right to considerate and compassionate care that safeguards their personal dignity and respects their values and preferences. A college health program recognizes the basic human rights of patients and encourages patients to assume responsibility for their own welfare. Such a health service includes the following characteristics: [...] Students are provided appropriate privacy, including protection from access to their confidential information by faculty and non-health service staff who are not responsible for direct health care, and by other students working at the health service not trained or qualified to provide care; [...] The need to assure continuity of care and to protect a patient's health and safety is balanced with a patient's rights to privacy and the confidentiality of provider-patient disclosures, as appropriate. Student disclosures and records are treated confidentially. Students are given the authority to approve or refuse their release in compliance with applicable state and federal laws; [...] Information is available to students and staff concerning the following: policy on the rights and responsibilities of patients;[...] [and] policy on treatment of an unemancipated minor not accompanied by an adult, consistent with applicable federal and state regulations. [...]

American College Health Association

A college health program maintains a health record system from which information can be retrieved promptly, with appropriate safeguards of confidential patient information. [...] Such a college health program has the following characteristics: The college health program develops and maintains an effective system for the collection, processing, maintenance, storage, retrieval, distribution, and safeguarding of patient health records. ³⁷

Emergency Departments

□ Common and statutory law generally has supported the physician or health care professional in providing emergency care for children in the ED without the consent of a parent or guardian. In addition, current federal law under the Emergency Medical Treatment and Active Labor Act (EMTALA) mandates a medical screening examination (MSE) for every patient seeking treatment in an ED of any hospital that participates in programs that receive federal funding, regardless of consent or reimbursement issues. EMTALA preempts

American Academy of Pediatrics, American College of Emergency Physicians, and five other organizations

Emergency Departments

American Academy of Pediatrics, American College of Emergency Physicians, and five other organizations (cont'd) conflicting or inconsistent state laws, essentially rendering the problem of obtaining consent for the emergency treatment of minors a nonissue at participating hospitals. [...]

Although the ED should attempt to contact the unaccompanied patient's parent or legal guardian to seek consent for treatment, the performance of the MSE and the stabilization of the patient with an identified [emergency medical condition] EMC must not be delayed. [...] In his comprehensive reference on EMTALA, Bitterman stated,

"Thus, under federal law, a minor can be examined, treated, stabilized, and even transferred to another hospital for emergency care without consent ever being obtained from the parent or legal guardian. Such care would not only be in the patient's best interest but also required by federal law." [...]

Although medical care for an emergency condition may need to proceed without prior assent or permission, the physician should seek consensus from the patient or family as soon as possible. If a conflict over consent or assent for treatment develops, to resolve the conflict the physician may need to evaluate the patient's emotional and intellectual maturity and understanding, the severity of the medical condition, the risks and benefits of treatment, the potential to defer therapy, and the basis for the refusal of treatment. In some cases the physician may need to involve the court or social service agencies to proceed with treatment against patient or parental will.

Financial reimbursement for the ED treatment of the unaccompanied minor may affect access to appropriate medical care and patient confidentiality. Adolescents usually are covered by their family's insurance or by Medicaid, but they may not have coverage for unaccompanied care, and they may not have the resources to pay for care themselves. As mentioned previously, EMTALA requires that an MSE be provided without consideration of reimbursement issues. Although state and federal programs exist to pay for children's health care needs, uncompensated charges may result from the EMTALA requirement of treatment for all without regard to payment. The ED should ensure that the financial issues surrounding a patient's treatment do not result in a breach of patient confidentiality, particularly if an unintended parental notification may result from the receipt of an itemized medical bill. The physician should discuss these ramifications of unaccompanied care with the minor patient as appropriate for the patient's level of maturity and understanding and seek assent from the patient for parental involvement, as may be required by patient privacy laws in some states, or honor the patient's wish for confidential care. [...]

Recommendations: 1. Appropriate medical care for the pediatric patient with an urgent or emergent condition should never be withheld or delayed because of problems with obtaining consent. 2. The physician or health care professional should be familiar with EMTALA federal regulations and state laws concerning consent for the treatment of minors. 3. Every clinic, office practice, and ED should develop written policies and guidelines that conform with federal and state laws regarding consent for the treatment of minors, including specific guidelines on financial billing, parental notification, and patient confidentiality for the unaccompanied minor. 4. The physician or health care professional should document in the patient medical record all

Emergency Departments

discussions of consent or assent, including the identity of the person providing consent or permission for treatment (the patient or parent or another adult acting on the parent's behalf), an assessment of the maturity and understanding of the pediatric patient, and the efforts made to obtain consent from the patient's legal guardian, if unavailable. 5. The physician or health care professional should always seek consent or assent for medical care from the pediatric patient as appropriate for the patient's development, age, and understanding. ¹⁶

- ☐ The medical screening, evaluation and necessary treatment of a minor in the emergency department should not be delayed because of consent issues. ³⁹
- ☐ [Regarding consent for evaluation and treatment of minors] There is no question that an evaluation by a health care provider must be done to determine if an emergency exists, and, if so, no consent is needed for initiating treatment. [...] States vary in consent statutes and case law. Each state has its own variations and exceptions. [...] Emergency physicians must be knowledgeable about their state consent laws and their departmental consent policy and have a mechanism to obtain consent from the court when necessary for the health and welfare of the child. [...] In an attempt to address the conflict between the rights and responsibilities of parent(s) or legal guardian(s) (henceforth referred to as "parent[s]") and the entitlement of minors to timely and confidential medical care, the legal guidelines regarding consent have grown complex. In the emergency department, misinterpretation of these guidelines can delay the delivery of medical care unnecessarily. Emergency physicians need to deliver the best care possible in a prompt and appropriate manner without undue restrictions imposed by the attainment of consent. [...] With a minor, an effort should be made to obtain consent from the parent(s), but not pursued to the point of detrimental delay in treatment. If treatment is given without prior consent from the parent(s), the parent(s) should be advised of the treatment rendered as soon as possible. [...] Consent issues involving minors and parent(s) are problematic. The laws strive to balance the interests of the minor, family, health care system, and public. The judicial system has no intent to deny or delay care to minors. The courts have not found physicians liable where appropriate, beneficial, and necessary medical care was given without consent. Emergency physicians' actions should be guided by common sense to provide the best care possible at all times. Emergency physicians should never allow the need for consent to deter them from delivering necessary care. It is crucial that documentation on the medical record sheet indicates the assessment of the need for consent, and, if indicated, determination of the competence of the party(ies) approached for consent, measures taken to obtain an informed consent, and identification of and resolution of conflict(s). 40

American Academy of Pediatrics, American College of Emergency Physicians, and five other organizations (cont'd)

> American College of Emergency Physicians

American College of Emergency Physicians

Managed Care Settings

Society for Adolescent Medicine

□ Due to their age and developmental status, many adolescents will only use necessary health care if they can obtain services in adolescent-friendly sites on a confidential basis. Therefore, managed care arrangements should incorporate protections for adolescents to receive confidential care and procedures allowing adolescents to give informed consent for their own care as allowed by state and federal law. [...] Co-payments, if required at all, should be minimal; co-payments should not be imposed for services such as family planning, screening for sexually transmitted infections, or substance abuse counseling and treatment that are related to adolescents' high risk behaviors and that adolescents are reluctant to seek other than on a confidential basis. ⁹⁴

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APPENDIX A: Contact Information for Organizations Represented In This Compendium ^a

Organization

American Academy of Child & Adolescent Psychiatry (AACAP)

3615 Wisconsin Avenue, NW Washington, DC 20016-3007 www.aacap.org

American Academy of Family Physicians (AAFP)

PO Box 11210

Shawnee Mission, KS 66207-1210

www.aafp.org

American Academy of Pediatric Dentistry (AAPD)

211 E. Chicago Avenue, Suite 700 Chicago, IL 60611-2663 www.aapd.org

American Academy of Pediatrics (AAP)

141 Northwest Point Boulevard Elk Grove Village, IL 60007-1098

www.aap.org

American College of Emergency Physicians (ACEP)

PO Box 619911 Dallas, Texas 75261-9911 www.acep.org

American College Health Association (ACHA)

PO Box 28937 Baltimore, MD 21240-8937

www.acha.org

American College of Obstetricians and Gynecologists (ACOG)

PO Box 96920

Washington, DC 20090-6920

www.acog.org

American College of Physicians (ACP)

190 N Independence Mall, West Philadelphia, PA 19106-1572 www.acponline.org

American College of Preventive Medicine (ACPM)

1307 New York Avenue, NW, Suite 200 Washington, DC 20005-4727 www.acpm.org

American Medical Association (AMA)

515 North State Street Chicago, IL 60610-4320

 $www.ama\hbox{-} assn.org/go/adolescenthe alth$

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Ann Echols, Program Coordinator, Scientific

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Gina Sandoval, Communications Manager

Darcy Steinberg, Division Director, Developmental

Pediatrics and Preventive Services, and Karen Smith, Manager, Developmental Pediatrics and Preventive

Services

Sonia Montgomery, Executive Offices Manager, and

Cal Chaney, JD, CAE, General Counsel and Executive

Director for Policy

Sharon Fisher, Communications Coordinator and Margaret Bridwell, ACHA Liaison to AMA – Partners

in Program Planning for Adolescent Health

(PIPPAH)

 ${\it Janet\ Chapin,\ Director,\ Division\ of\ Women's\ Health}$

Issues, and Lisa Goldstein, Director, Adolescent

Health Care

Jack Ginsberg, Director, Health Policy Analysis &

Research and Alex Bamiagis, Health Policy Associate

Michael Barry, Deputy Director

Missy Fleming, Program Director, Child and Adolescent Health, and Kelly Towey, PIPPAH

Program Manager

Susan Terwilliger, ANF Project Director, and Debbie Lao Regalario, Project Manager, ANF PIPPAH

Jane Edgerton, Project Manager, Office of Children's

Dolores C. Jones, Director of Practice, Education, and

Ted Feinberg, Assistant Executive Director

Contact person

Professional Affairs

Affairs

APPENDIX A: Contact Information for Organizations Represented In This Compendium (control) a

Organization

American Nurses Association (ANA)

8515 Georgia Avenue, Suite 400 Silver Spring, MD 20910 www.nursingworld.org

American Psychiatric Association (APA)

1000 Wilson Boulevard, Suite 1825 Arlington, VA 22209-3901

www.psych.org

Mary Campbell, Children, Youth and Families Officer American Psychological Association (APA)

750 First Street, NE Washington, DC 20002-4242

www.apa.org

Barbara Hatcher, Director of Scientific and American Public Health Association (APHA)

800 I Street, NW

Washington, DC 20001-3710

www.apha.org

American School Health Association (ASHA) Marcia Rubin, Director, Research & Sponsored

Programs 7263 State Route 43

PO Box 708 Kent, OH 44240

www.ashaweb.org

National Assembly on School-Based Health Care (NASBHC) John Schlitt, MSW, Executive Director

666 11th Street, NW, Suite 735 Washington, DC 20001 www.nasbhc.org

National Association of Pediatric Nurse Practitioners (NAPNAP)

20 Brace Road, Suite 200 Cherry Hill, NJ 08034-2634

www.napnap.org

Research, and Bonnie Gance-Cleveland, Adolescent

Liaison

National Association of School Psychologists (NASP)

4340 East West Highway, Suite 402 Bethesda, MD 20814

www.nasponline.org

Laurie Emmer, Senior Policy Associate, Adolescent National Association of Social Workers (NASW)

Health

750 First Street, NE, Suite 700 Washington, DC 20002-4241 www.socialworkers.org

Abigail English, Chair, Advocacy Committee Society for Adolescent Medicine (SAM)

1916 Copper Oaks Circle Blue Springs, MO 64015

www.adolescenthealth.org

^a Individuals listed here assisted with the preparation and review of this compendium. Their willingness to contribute to this document is sincerely appreciated. Any errors or omissions should be attributed to the editors.

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□ National Association of Social Workers (NASW)	7, 9, 10, 12, 14, 24, 27, 31, 33, 42-43, 43, 55, 79
☐ Society for Adolescent Medicine (SAM)	6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 19, 20, 21, 22, 23, 24, 26, 29, 30, 31, 32, 44-46, 55, 55-58, 58, 59, 60, 61, 68, 72, 82

APPENDIX C: Significance of the HIPAA Privacy Rule for Health Care of Adolescents

What are the federal medical privacy regulations?

The "Standards for Privacy of Individually Identifiable Health Information" are federal medical privacy regulations (often referred to as the "HIPAA Privacy Rule") that broadly regulate access to and disclosure of confidential medical information. These regulations were promulgated by the Department of Health and Human Services (HHS) pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

When was the HIPAA Privacy Rule issued?

Proposed regulations were initially published in November 1999. Following the submission of thousands of comments, a final rule was published on December 28, 2000. The effective date of this final rule was postponed until April 14, 2001. Proposed modifications were published in March 2002. Following a public comment period, final modifications were issued on August 14, 2002.

What is the scope of the HIPAA Privacy Rule?

The HIPAA Privacy Rule addresses a broad range of issues related to the privacy of individuals' health information. The Rule creates new rights for individuals to have access to their health information and medical records. It also specifies when an individual's authorization is required for disclosure of confidential health information, referred to as "protected health information," and when protected health information may be used or disclosed without authorization. The regulations also contain provisions that are specific to the health information of minor children.

Who must comply with the HIPAA Privacy Rule?

The HIPAA Privacy Rule applies to "covered entities," which include health plans, health care providers, and health care clearinghouses. According to the way each of these is defined, the vast majority of health care professionals who provide care to adolescents are required to comply with the HIPAA Privacy Rule.

What is the implementation date for the HIPAA Privacy Rule?

Large health plans, health care providers, and health care clearinghouses were required to comply with the rules by April 14, 2003. Small health plans were required to comply with the rules by April 14, 2004.

Do the general requirements of the HIPAA Privacy Rule apply to the care of adolescents?

The HIPAA Privacy Rule contains numerous provisions that affect the confidentiality of information regarding health care provided to adolescents. Most of the general provisions of the HIPAA Privacy Rule are relevant, even though they are not specific to adolescents. They also are applicable to information about health care that is provided to younger children and to adults. Adolescents who are age 18 or older are adults and have the same rights under the Privacy Rule as other individuals who are adults. In addition, there are provisions of the Rule that address the specific issues related to the health information of minors, including adolescents who are under the age of 18 and not emancipated.

When may protected health information be used or disclosed without an individual's authorization? Generally, the HIPAA Privacy Rule permits a covered entity to use and disclose an individual's protected health information without the individual's permission for treatment, payment, or health care operations of its own. A covered entity may also disclose protected health information without an individual's permission to other covered entities under specific circumstances. In particular, information may be disclosed to a health care provider for treatment or payment activities and in other specified situations.

Does the HIPAA Privacy Rule have special requirements that apply to public health?

Many public health agencies, organizations, and practitioners are covered entities under the HIPAA Privacy Rule and are required to comply with the Rule generally. The Privacy Rule also contains specific public health provisions. In particular, The HIPAA Privacy Rule allows covered entities to disclose an individual's protected health information without the individual's authorization for the purpose of controlling disease, injury, or disability. This

includes reporting of disease, injuries, births, and deaths, as well as conducting public health surveillance, investigations, and interventions.

Does the HIPAA Privacy Rule have special requirements that apply to research?

The HIPAA Privacy Rule contains numerous provisions that may affect the conduct of research. Researchers need to understand the relationship between the HIPAA Privacy Rule and the HHS and FDA Protection of Human Subjects regulations (45 CFR Part 46 and 21 CFR Parts 50 and 56). In addition there are important issues to understand about the specific application of the Privacy Rule to research. De-identified health information is not protected health information under the Rule. Protected health information may be used and disclosed for research with the written permission or authorization of the individual. In limited circumstances, protected health information may be used in research without an individual's authorization.

Does the HIPAA Privacy Rule have special requirements that apply to information in schools? The HIPAA Privacy Rule specifies that information covered by the Federal Educational Rights and Privacy Act (FERPA) is not considered protected health information for purposes of the Privacy Rule. FERPA generally applies to information contained in a student's educational record, including some health information. However, some information in schools is protected under the Privacy Rule.

How does the HIPAA Privacy Rule treat adolescents who are minors and their parents? When adolescents are unemancipated minors, their parents (including guardians and persons acting *in loco parentis*) generally are considered their "personal representatives." As personal representatives, parents exercise any rights under the Rule with respect to the minors' protected health information, including the right to access that information. However, parents are not automatically treated as the personal representatives of unemancipated minors who are considered "individuals" under the HIPAA Privacy Rule.

When is a minor an "individual" under the HIPAA Privacy Rule?

A minor is considered an individual under the HIPAA Privacy Rule in one of three specific circumstances. The first situation is one in which the minor has the right to consent to health care and has consented, such as when a minor has consented to treatment of an STI under a state minor consent law. The second situation is one in which the minor may legally receive the care without the consent of a parent, and the minor or another individual or a court has consented to the care, such as when a minor has requested and received court approval to have an abortion without parental consent or notification. The third situation is one in which a parent has assented to an agreement of confidentiality between the health care provider and the minor. In each of these circumstances, the minor is treated as the "individual" who may exercise rights under the Privacy Rule and the parent is not the personal representative of the minor. In these circumstances, the minor also may choose to have the parent act as the personal representative or not.

When a minor is the individual and a parent is not the personal representative?

When a minor is the individual and a parent is not the personal representative of the minor, the minor may exercise most of the same rights as an adult under the regulations. With respect to the specific question of whether a parent who is not the personal representative of the minor may have access to the minor's protected health information, the regulations defer to state or other applicable law. If state or other law explicitly requires information to be disclosed to a parent, the regulations allow a health care provider to comply with that law and to disclose the information. If state or other law explicitly permits, but does not require, information to be disclosed to a parent, the regulations allow a health care provider to exercise discretion to disclose or not. If state or other law prohibits disclosure of information to a parent without the consent of the minor, the regulations do not allow a health care provider to disclose it without the minor's consent. If state or other law is silent or unclear on the question, a covered entity has discretion to determine whether or not to grant access to a parent to the protected health information. In such cases the determination must be made by a health care professional exercising professional judgment.

What does the HIPAA Privacy Rule mean for health care providers in a specific state?

Every state has numerous laws that allow minors to give their own consent for health care. In addition, some states have laws that specify the circumstances under which parents may or may not have access to information regarding the care for which minors may give their own consent. The federal privacy regulations defer to those laws, and other laws, to the extent that they prohibit, permit, or require disclosure of information to parents. In particular, if state or other law is silent or unclear on the issue of parents' access to minors' confidential information, covered entities, including health providers, have discretion to determine whether or not to grant access to parents, as long as the decision is made by a health care professional exercising professional judgment. For adults, including adolescents age 18 or older, the federal regulations defer to state laws that provide stronger privacy protections than the federal rules, but if state laws provide weaker protection, the federal rules control.

What happens if a parent is suspected of domestic violence, abuse, or neglect?

When a parent is suspected of domestic violence, abuse, or neglect of a child, including an adolescent, a health care provider may limit the parent's access to and control over protected health information about the child by not treating the parent as the personal representative of the child.

How does a health care provider know what is required?

☐ Health Privacy Project. http://www.healthprivacy.org/

☐ Office for Civil Rights. http://www.hhs.gov/ocr/hipaa/

□ NIH. http://privacyruleandresearch.nih.gov/

This overview does not provide legal advice. Health care providers should consult with legal counsel to understand how the HIPAA Privacy Rule applies to them and how to comply with the Rule.

Where can additional information about the HIPAA Privacy Rule be found?

REGULATIONS

	Standards for Privacy of Individually Identifiable Health Information. 45 C.F.R. Parts 160 and 164. This is the official codified version of the HIPAA Privacy Rule.	
	Standards for Privacy of Individually Identifiable Health Information. Final Rule, 65 Federal Register 82461 (Dec. 28, 2000). This is the final rule issued in December 2000, including the extensive commentary from the Department of Health & Human Services that accompanied the rule itself.	
	Standards for Privacy of Individually Identifiable Health Information. Final Rule, 67 Federal Register 53182 (Aug. 14, 2002). This is the final rule issued in August 2002 that contains the modifications to the December 2000 version, including the extensive commentary from the Department of Health & Human Services that accompanied the rule itself.	
	U.S. Department of Health and Human Services, Office for Civil Rights. <i>Regulation Text</i> . (45 CFR Parts 160 and 164) (Unofficial Version). Available at: http://www.hhs.gov/ocr/combinedregtext.pdf. This is the unofficial merged version of the HIPAA Privacy Rule, the Security Standards, and General Administrative Requirements that have been officially codified in Title 45 of the Code of Federal Regulations, Parts 160 and 164.	
Websites		
	CDC. http://www.cdc.gov/privacyrule/	

□ Note: Many of the organizations whose policies appear in this Compendium have posted materials about the HIPAA Privacy Rule on their websites. The addresses of those websites are included in Appendix A.

SUMMARIES

Health Privacy Project. Summary of HIPAA Privacy Rule. Available at:
http://www.healthprivacy.org/usr_doc/RegSummary2002.pdf.

□ Office for Civil Rights, U.S. Department of Health and Human Services. OCR Privacy Brief: Summary of the HIPAA Privacy Rule. Available at: http://www.hhs.gov/ocr/privacysummary.pdf.

BOOKS, MONOGRAPHS, AND ARTICLES

- □ Centers for Disease Control and Prevention. HIPAA Privacy Rule and public health: Guidance from CDC and the U.S. Department of Health and Human Services. *MMWR* 2003; 52(Suppl):1-12.
- □ National Institutes of Health, U.S. Department of Health and Human Services. Protecting Personal Health Information in Research: Understanding the HIPAA Privacy Rule. NIH Publication Number 03-5388. Available at: http://privacyruleandresearch.nih.gov/.
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