

PERSONAL REPRESENTATIVES

SECTION 164.502(g)

As Contained in the HHS Final HIPAA Privacy Rules

Proposed Revisions to HHS Regulations

Personal Representatives - § 164.502(g)

1. Standard: personal representatives. As specified in this paragraph, a covered entity must, except as provided in paragraphs (g)(3) and (g)(5) of this section, treat a personal representative as the individual for purposes of this subchapter.

2. Implementation specification: adults and emancipated minors. If under applicable law a person has authority to act on behalf of an individual who is an adult or an emancipated minor in making decisions related to health care, a covered entity must treat such person as a personal representative under this subchapter, with respect to protected health information relevant to such personal representation.

3. Implementation specification: unemancipated minors.

i. If under applicable law a parent, guardian, or other person acting in loco parentis has authority to act on behalf of an individual who is an unemancipated minor in making decisions related to health care, a covered entity must treat such person as a personal representative under this subchapter, with respect to protected health information relevant to such personal representation, except that such person may not be a personal representative of an unemancipated minor, and the minor has the authority to act as an individual, with respect to protected health information pertaining to a health care service, if:

A. The minor consents to such health care service; no other consent to such health care service is required by law, regardless of whether the consent of another person has also been obtained; and the minor has not requested that such person be treated as the personal representative;

B. The minor may lawfully obtain such health care service without the consent of a parent, guardian, or other person acting in loco parentis, and the minor, a court, or another person authorized by law consents to such health care service; or

C. A parent, guardian, or other person acting in loco parentis assents to an agreement of confidentiality between a covered health care provider and the minor with respect to such health care service.

ii. Notwithstanding the provisions of paragraph (g)(3)(i) of this section:

A. A covered entity may disclose protected health information about an unemancipated minor to a parent, guardian, or other person acting in loco parentis if an applicable provision of State or other law, including applicable case law, permits or requires such disclosure; and

B. A covered entity may not disclose protected health information about an unemancipated minor to a parent, guardian, or other person acting in loco parentis if an applicable provision of State or other law, including applicable case law, prohibits such disclosure.

iii. Notwithstanding the provisions of paragraph (g)(3)(i) of this section, a covered entity must, consistent with State or other applicable law, provide a right of access, as set forth in § 164.524 to either:

A. A parent, guardian, or other person acting in loco parentis, as the personal representative of the unemancipated minor;

B. The unemancipated minor; or

C. Both.

4. Implementation specification: deceased individuals. If under applicable law an executor, administrator, or other person has authority to act on behalf of a deceased individual or of the individual's estate, a covered entity must treat such person as a personal representative under this subchapter, with respect to protected health information relevant to such personal representation.

5. Implementation specification: abuse, neglect, endangerment situations. Notwithstanding a State law or any requirement of this paragraph to the contrary, a covered entity may elect not to treat a person as the personal representative of an individual if:

i. The covered entity has a reasonable belief that:

A. The individual has been or may be subjected to domestic violence, abuse, or neglect by such person; or

B. Treating such person as the personal representative could endanger the individual; and

ii. The covered entity, in the exercise of professional judgment, decides that it is not in the best interest of the individual to treat the person as the individual's personal representative.

HHS Regulations

Personal Representatives - § 164.502(g)

1. Standard: personal representatives. As specified in this paragraph, a covered entity must, except as provided in paragraphs (g)(3) and (g)(5) of this section, treat a personal representative as the individual for purposes of this subchapter.

2. Implementation specification: adults and emancipated minors. If under applicable law a person has authority to act on behalf of an individual who is an adult or an emancipated minor in making decisions related to health care, a covered entity must treat such person as a personal representative under this subchapter, with respect to protected health information relevant to such personal representation.

3. Implementation specification: unemancipated minors. If under applicable law a parent, guardian, or other person acting in loco parentis has authority to act on behalf of an individual who is an unemancipated minor in making decisions related to health care, a covered entity must treat such person as a personal representative under this subchapter, with respect to protected health information relevant to such personal representation, except that such person may not be a personal representative of an unemancipated minor, and the minor has the authority to act as an individual, with respect to protected health information pertaining to a health care service, if:

i. The minor consents to such health care service; no other consent to such health care service is required by law, regardless of whether the consent of another person has also been obtained; and the minor has not requested that such person be treated as the personal representative;

ii. The minor may lawfully obtain such health care service without the consent of a parent, guardian, or other person acting in loco parentis, and the minor, a court, or another person authorized by law consents to such health care service; or

iii. A parent, guardian, or other person acting in loco parentis assents to an agreement of confidentiality between a covered health care provider and the minor with respect to such health care service.

4. Implementation specification: deceased individuals. If under applicable law an executor, administrator, or other person has authority to act on behalf of a deceased individual or of the individual's estate, a covered entity must treat such person as a

personal representative under this subchapter, with respect to protected health information relevant to such personal representation.

5. Implementation specification: abuse, neglect, endangerment situations. Notwithstanding a State law or any requirement of this paragraph to the contrary, a covered entity may elect not to treat a person as the personal representative of an individual if:

i. The covered entity has a reasonable belief that:

A. The individual has been or may be subjected to domestic violence, abuse, or neglect by such person; or

B. Treating such person as the personal representative could endanger the individual; and

ii. The covered entity, in the exercise of professional judgment, decides that it is not in the best interest of the individual to treat the person as the individual's personal representative.

HHS Description

Personal Representatives

In the proposed rule we defined “individual” to include certain persons who were authorized to act on behalf of the person who is the subject of the protected health information. For adults and emancipated minors, the NPRM provided that “individual” includes a legal representative to the extent to which applicable law permits such legal representative to exercise the individual's rights in such contexts. With respect to unemancipated minors, we proposed that the definition of “individual” include a parent, guardian, or person acting in loco parentis, (hereinafter referred to as “parent”) except when an unemancipated minor obtained health care services without the consent of, or notification to, a parent. Under the proposed rule, if a minor obtained health care services under these conditions, the minor would have had the exclusive rights of an individual with respect to the protected health information related to such health care services.

In the final rule, the definition of “individual” is limited to the subject of the protected health information, which includes unemancipated minors and other individuals who may lack capacity to act on their own behalf. We remove from the definition of “individual” the provisions regarding legal representatives. The circumstances in which a representative must be treated as an individual for purposes of this rule are addressed in a separate standard titled “personal representatives.” (§ 164.502(g)). The standard regarding personal representatives incorporates some changes to the proposed provisions regarding legal representatives. In general, under the final regulation, the “personal representatives” provisions are directed at the more formal representatives, while § 164.510(b) addresses situations in which persons are informally acting on behalf of an individual.

With respect to adults or emancipated minors, we clarify that a covered entity must treat a person as a personal representative of an individual if such person is, under applicable law, authorized to act on behalf of the individual in making decisions related to health care. This includes a court-appointed guardian and a person with a power of attorney, as set forth in the NPRM, but may also include other persons. The authority of a personal representative under this rule is limited: the representative must be treated as the individual only to the extent that protected

health information is relevant to the matters on which the personal representative is authorized to represent the individual. For example, if a person's authority to make health care decisions for an individual is limited to decisions regarding treatment for cancer, such person is a personal representative and must be treated as the individual with respect to protected health information related to the cancer treatment of the individual. Such a person is not the personal representative of the individual with respect to all protected health information about the individual, and therefore, a covered entity may not disclose protected health information that is not relevant to the cancer treatment to the person, unless otherwise permitted under the rule. We intend this provision to apply to persons empowered under state or other law to make health related decisions for an individual, whether or not the instrument or law granting such authority specifically addresses health information.

In addition, we clarify that with respect to an unemancipated minor, if under applicable law a parent may act on behalf of an unemancipated minor in making decisions related to health care, a covered entity must treat such person as a personal representative under this rule with respect to protected health information relevant to such personal representation, with three exceptions. Under the general rule, in most circumstances the minor would not have the capacity to act as the individual, and the parent would be able to exercise rights and authorities on behalf of the minor. Under the exceptions to the rule on personal representatives of unemancipated minors, the minor, and not the parent, would be treated as the individual and able to exercise the rights and authorities of an individual under the rule. These exceptions occur if: (1) the minor consents to a health care service; no other consent to such health care service is required by law, regardless of whether the consent of another person has also been obtained; and the minor has not requested that such person be treated as the personal representative; (2) the minor may lawfully obtain such health care service without the consent of a parent, and the minor, a court, or another person authorized by law consents to such health care service; or (3) a parent assents to an agreement of confidentiality between a covered health care provider and the minor with respect to such health care service. We note that the definition of health care includes services, but we use "health care service" in this provision to clarify that the scope of the rights of minors under this rule is limited to the protected health information related to a particular service.

Under this provision, we do not provide a minor with the authority to act under the rule unless the state has given them the ability to obtain health care without consent of a parent, or the parent has assented. In addition, we defer to state law where the state authorizes or prohibits disclosure of protected health information to a parent. See part 160, subpart B, Preemption of State Law. This rule does not affect parental notification laws that permit or require disclosure of protected health information to a parent. However, the rights of a minor under this rule are

not otherwise affected by such notification.

In the final rule, the provision regarding personal representatives of deceased individuals has been changed to clarify the provision. The policy has not changed substantively from the NPRM.

Finally, we added a provision in the final rule to permit covered entities to elect not to treat a person as a personal representative in abusive situations. Under this provision, a covered entity need not treat a person as a personal representative of an individual if the covered entity, in the exercise of professional judgment, decides that it is not in the best interest of the individual to treat the person as the individual's personal representative and the covered entity has a reasonable belief that the individual has been or may be subjected to domestic violence, abuse, or neglect by such person, or that treating such person as the personal representative could endanger the individual.

Section 164.502(g) requires a covered entity to treat a person that meets the requirements of a personal representative as the individual (with the exceptions described above). We note that disclosure of protected health information to a personal representative is mandatory under this rule only if disclosure to the individual is mandatory. Disclosure to the individual is mandatory only under §§ 164.524 and 164.528. Further, as noted above, the personal representative's rights are limited by the scope of its authority under other law. Thus, this provision does not constitute a general grant of authority to personal representatives.

We make disclosure to personal representatives mandatory to ensure that an individual's rights under §§ 164.524 and 164.528 are preserved even when individuals are incapacitated or otherwise unable to act for themselves to the same degree as other individuals. If the covered entity were to have the discretion to recognize a personal representative as the individual, there could be situations in which no one could invoke an individual's rights under these sections.

We continue to allow covered entities to use their discretion to disclose certain protected health information to family members, relatives, close friends, and other persons assisting in the care of an individual, in accordance with § 164.510(b). We recognize that many health care decisions take place on an informal basis, and we permit disclosures in certain circumstance to permit this practice to continue. Health care providers may continue to use their discretion to address these informal situations.

HHS Response to Comments Received Personal Representatives

Comment: It was observed that under the proposed regulation, legal representatives with “power of attorney” for matters unrelated to health care would have unauthorized access to confidential medical records. Commenters recommended that access to a person's protected health information be limited to those representatives with a “power of attorney” for health care matters only. Related comments asked that the rule limit the definition of “power of attorney”

to include only those instruments granting specific power to deal with health care functions and health care records.

Response: We have deleted the reference to “power of attorney.” Under the final rule, a person is a personal representative of a living individual if, under applicable law, such person has authority to act on behalf of an individual in making decisions related to health care. “Decisions relating to health care” is broader than consenting to treatment on behalf of an individual; for example, it would include decisions relating to payment for health care. We clarify that the rights and authorities of a personal representative under this rule are limited to protected health information relevant to the rights of the person to make decisions about an individual under other law. For example, if a husband has the authority only to make health care decisions about his wife in an emergency, he would have the right to access protected health information related to that emergency, but he may not have the right to access information about treatment that she had received ten years ago.

We note that the rule for deceased individuals differs from that of living individuals. A person may be a personal representative of a deceased individual if they have the authority to act on behalf of such individual or such individual's estate for any decision, not only decisions related to health care. We create a broader scope for a person who is a personal representative of a deceased individual because the deceased individual can not request that information be disclosed pursuant to an authorization, whereas a living individual can do so.

Comment: Some commenters asked that the NPRM provision allowing informal decision-makers access to the protected health information of an incapacitated individual should be maintained in the final rule.

Response: We agree with the commenters, and retain permission for covered entities to share protected health information with informal decision makers, under conditions specified in § 164.510(b). A person need not be a personal representative for such disclosure of protected health information to be made to an informal decision-maker.

Comment: Commenters urged that individuals with mental retardation, who can provide verbal agreement or authorization, should have control over dissemination of their protected health information, in order to increase the privacy rights of such individuals.

Response: Individuals with mental retardation have control over dissemination of their protected health information under this rule to the extent that state law provides such individuals with the capacity to act on their own behalf. We note that a covered entity need not disclose information pursuant to a consent or authorization. Therefore, even if state law determines that an individual with mental retardation is not competent to act and a personal representative provides authorization for a disclosure, a covered entity may choose not to disclose such information if the individual who lacks capacity to act expresses his or her desire that such information not be disclosed.

Comment: A commenter suggested that the final rule should provide health plans with a set of

criteria for formally identifying an incapacitated individual's decision-maker. Such criteria would give guidance to health plans that would help in not releasing information to the wrong person.

Response: The determination about who is a personal representative under this rule is based on state or other applicable law. We require that a covered entity verify the authority of a personal representative, in accordance with § 164.514(h) in order to disclose information to such person.

Comment: Commenters were troubled by the inclusion of minors in the definition of “individual” and believed that the presumption should be that parents have the right to care for their children.

Response: We agree that a parent should have access to the protected health information about their unemancipated minor children, except in limited circumstances based on state law. The approach in the final rule helps clarify this policy. The definition of “individual” is simplified in the final rule to “the person who is the subject of protected health information.” (§ 164.501). We created a new section (§ 164.502(g)) to address “personal representatives,” which includes parents and guardians of unemancipated minors. Generally, we provide that if under applicable law a parent has authority to act on behalf of an unemancipated minor in making decisions relating to health care about the minor, a covered entity must treat the parent as the personal representative with respect to protected health information relevant to such personal representation. The regulation provides only three limited exceptions to this rule based upon current state law and physician practice.

Comment: Many commenters agreed with our approach in the NPRM to give minors who may lawfully access health care the rights to control the protected health information related to such health care.

Several commenters disagreed with this approach and recommended that where states allow minors too much independence from parents, the rule should not defer to state law. One commenter suggested that we give an individual the right to control protected health information only when the individual reaches the age of majority.

Response: In the final rule, the parent, as the personal representative of a minor child, controls the protected health information about the minor, except that the parent does not act as a personal representative of the minor under the rule in three limited circumstances based on state consent law and physician practice. The final rule defers to consent laws of each state and does not attempt to evaluate the amount of control a state gives to a parent or minor. If a state provides an alternative means for a minor to obtain health care, other than with the consent of a parent, this rule preserves the system put in place by the state.

The first two exceptions, whereby a parent is not the personal representative for the minor and the minor can act for himself or herself under the rule, occur if the minor consents to a health care service, and no other consent to such health care service is required by law, or when the minor may lawfully obtain a health care service without the consent of a parent, and the minor,

a court, or another person authorized by law consents to such service. The third exception is based on guidelines of the American Pediatric Association, current practice, and agreement by parents. If a parent assents to an agreement of confidentiality between a covered provider and a minor with respect to a health care service, the parent is not the personal representative of the minor with respect to the protected health information created or received subject to that confidentiality agreement. In such circumstances, the minor would have the authority to act as an individual, with respect to such protected health information.

Comment: Some commenters requested that we permit minors to exercise the rights of an individual when applicable law requires parental notification as opposed to parental consent.

Response: We adopt this policy in the final rule. If the minor consents to a health care service, and no other consent to such health care service is required by law, regardless of whether the consent of another person has also been obtained or notification to another person has been given, only the minor may be treated as the individual with respect to the protected health information relating to such health care service. The rule does not affect state law that authorizes or requires notification to a parent of a minor's decision to obtain a health care service to the extent authorized or required by such law. In addition, state parental notification laws do not affect the rights of minors under this regulation.

Comment: Some commenters requested clarification that when a minor may obtain a health care service without parental consent and voluntarily chooses to involve a parent, the minor retains the rights, authorities and confidentiality protections established in this rule.

Response: We agree that minors should be encouraged to voluntarily involve a parent or other responsible adult in their health care decisions. The rule is not intended to require that minors choose between involving a parent and maintaining confidentiality protections. We have added language in § 164.502(g)(3)(i) to clarify that when a minor consents to a health care service and no other consent is required by law, if the minor voluntarily chooses to involve a parent or other adult, the minor nonetheless maintains the exclusive ability to exercise their rights under the rule.

This is true even if a parent or other person also has consented to the health care service for which the minor lawfully consented. Under the rule, a minor may involve a parent and still preserve the confidentiality of their protected health information. In addition, a minor may choose to have a parent act as his or her personal representative even if the minor could act on his or her own behalf under the rule. If the minor requests that a covered entity treat a parent as his or her personal representative, the covered entity must treat such person as the minor's personal representative even if the minor consents to a health care service and no other consent to such health care service is required by law.

Comment: Some commenters requested that the rule provide for the preservation of patient confidences if a health care provider and a minor patient enter into an agreement of confidentiality and a parent assents to this arrangement.

Response: We have addressed this concern in the final rule by adding a provision that ensures that a minor maintains the confidentiality protections provided by the rule for information that is created or received pursuant to a confidential communication between a provider and a minor when the minor's parent assents to an agreement of confidentiality between the provider and the minor. (§ 164.502(g)(3)(ii)). The American Academy of Pediatrics Guidelines for Health Supervision III, which are meant to serve as “a framework to help clinicians focus on important issues at developmentally appropriate time intervals,” recommends that physicians interview children alone beginning at the age of twelve (or as early as the age of ten if it is comfortable for the child). This recommendation is based on the fact that adolescents tend to underutilize existing health care resources, in part, because of a concern for confidentiality. The recommended interview technique in the Guidelines states that the provider discuss the rules of confidentiality with the adolescent and the parent and that the adolescent's confidentiality should be respected. We do not intend to interfere with these established protocols or current practices. Covered entities will need to establish procedures to separate protected health information over which the minor maintains control from protected health information with respect to which the minor's parent has rights as a personal representative of the minor.

A covered provider may disclose protected health information to a parent, regardless of a confidentiality agreement, if there is an imminent threat to the minor or another person, in accordance with § 164.512(j)(1)(i).

Comment: Several commenters suggested that we add a provision in the final rule to provide minors and parents with concurrent rights under certain circumstances, particularly when the minor reaches 16 years of age or when a parent authorizes his or her minor child to exercise these rights concurrently.

Response: We do not add such provision in the final rule. We believe that establishing concurrent rights through this rule could result in problems that effect the quality of health care if the minor and the parent were to disagree on the exercise of their rights. The rule would not prevent a parent from allowing a minor child to make decisions about his or her protected health information and acting consistently with the minor's decision. In all cases, either the parent has the right to act for the individual with respect to protected health information, or the minor has the right to act for himself or herself. The rule does not establish concurrent rights for parents and minors.

Comment: Commenters requested clarification about the rights of an adult or emancipated minor with respect to protected health information concerning health care services rendered while the person was an unemancipated minor.

Response: Once a minor becomes emancipated or attains the age of majority, as determined by applicable state law, the parent is no longer the personal representative under § 164.502(g)(3) of such individual, unless the parent has the authority to act on behalf of the individual for some reason other than their authority as a parent. An adult or emancipated minor has rights under the rule with respect to all protected health information about them, including information obtained while the individual was an unemancipated minor.

Comment: One commenter pointed out that language in the definition of individual in the NPRM that grants a minor the rights of an individual when he or she “lawfully receives care without the consent of, or notification to, a parent . . .” would have the effect of granting rights to an infant minor who receives emergency care when the parent is not available.

Response: This result was not our intent. We have changed the language in § 164.502(g)(3)(i) of the final rule to provide a minor the right to act as an individual when the minor can obtain care without the consent of a parent and the minor consents to such care. Because an infant treated in an emergency situation would not be able to consent to care, the infant's parent would be treated as the personal representative of the infant. Section 164.502(g)(3)(ii) provides that the parent is not the personal representative of the minor under the rule if the minor may obtain health care without the consent of a parent and the minor, a court, or another person authorized by law consents to such service. If an infant obtains emergency care without the consent of a parent, a health care provider may provide such care without consent to treatment. This situation would fall outside the second exception, and the parent would remain the personal representative of the minor.

Comment: Commenters were concerned about the interaction of this rule with FERPA with respect to parents' right to access the medical records of their children.

Response: We direct the commenters to a discussion of the interaction between our rule and FERPA in the "Relationship to Other Federal Laws" section of the preamble.