

MEMORANDUM

TO: NC Association of Local Health Directors
FROM: Jill Moore, JD, MPH
RE: HIE Opt-Out Procedures for Unemancipated Minors
DATE: May 16, 2017

Background

NC HealthConnex is an electronic network operated by the NC Health Information Exchange Authority (NC HIEA) pursuant to North Carolina law. G.S. Ch. 90, Art. 29B. All Medicaid providers in North Carolina must connect to NC HealthConnex by February 1, 2018. S.L. 2015-241, sec. 12A.5.(a). Medicaid providers and specified other health care providers are also required to submit certain information through the HIE network as a condition of receiving state funds and Medicaid funds. G.S. 90-414.4.

State law requires the NC HIEA to provide a procedure whereby individuals may opt out of having their protected health information (PHI) disclosed through the network. NC HIEA has created a form that an individual may sign to exercise the opt-out right. However, NC HealthConnex does not permit unemancipated minors to sign the opt-out form—rather, the form requires the signature of the unemancipated minor's parent or guardian. This applies even when the minor is treated pursuant to G.S. 90-21.5, a state law that authorizes minors to consent to certain health care services and does not require the consent of any other person for the specified services.

When a minor receives care under G.S. 90-21.5, both the HIPAA Privacy Rule and a state statute (G.S. 90-21.4(b)) apply to information related to the care. Both of these laws expressly identify the minor as the person who may authorize disclosures of such information. HIPAA also expressly grants the authority to exercise HIPAA's individual rights to the minor—not the minor's parent or guardian—when care is received pursuant to a law such as G.S. 90-21.5. However, the parent or guardian remains the appropriate person to exercise individual rights under HIPAA with respect to most other health care that an unemancipated minor receives. 45 C.F.R. 164.502(g)(3). This creates a situation in which an unemancipated minor's medical record may include two categories of information: PHI for which the minor is the appropriate person to exercise the rights of an individual under both HIPAA and state law, and PHI for which the minor's parent or guardian is the appropriate person.

At present, NC HealthConnex lacks the ability to accommodate partial opt-outs. If an opt-out form is completed for an individual, all PHI pertaining to the individual is opted out. This is the reason provided for requiring a parent or guardian to sign an unemancipated minor's opt-out form. However, this procedure raises the question of whether failing to provide a procedure for minors to opt out information about care received under G.S. 90-21.5 is in conflict with either HIPAA or state law.

Brief Opinion

An unemancipated minor receiving services under G.S. 90-21.5 should be given the opportunity to opt out of an HIE with respect to information related to those services. Failing to provide the minor an opt-out opportunity is clearly in tension with HIPAA, and it may even constitute a violation. When a minor receives care under a law such as G.S. 90-21.5, HIPAA requires the provider to treat the minor as the "individual," which means that the minor is the appropriate person to authorize disclosures of information and exercise the individual rights that HIPAA affords, including the right to request restrictions on disclosures of information. Further, the state HIE law expressly creates a right to opt out of the exchange operated by NC HIEA, gives that right to the individual, and incorporates HIPAA's definition of the term individual. Finally, if a minor is not provided the opportunity to opt out, the potential for information about the minor's treatment to be disclosed in violation of G.S. 90-21.4(b) may be increased.

Discussion

1. An unemancipated minor receiving services under G.S. 90-21.5 is an "individual" for HIPAA purposes.

Minors receiving services under GS 90-21.5 are treated as the "individual" under HIPAA. 45 CFR 164.502(g)(3)(i)(A) provides the general rule that a parent, guardian, or person acting in loco parentis must be treated as an unemancipated minor's personal representative, "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 services 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; ...*" (emphasis added).

In other words, if the minor gives consent for the health care and no other consent is required by law, the minor must be treated as the individual and the minor's parent/guardian may not be treated as the minor's personal representative unless the minor requests it.

2. Both state law and HIPAA support the conclusion that the decision of whether to opt out of an HIE should be made by the "individual."

The state HIE law expressly gives the authority to opt out of the exchange operated by NC HIEA to the individual, G.S. 90-414.10(a), and incorporates HIPAA's definition of individual, G.S. 90-414.3(10).

Multiple provisions of HIPAA also support the idea that the individual is the appropriate person to exercise opt-out authority. While the HIPAA regulations do not specifically address opt-in/opt-out forms for HIEs, they consistently give any authority that exists to control the flow of PHI to the individual. For example, the individual is the person who may authorize, or decline to authorize, the disclosure of PHI to third parties. 45 CFR 164.508. The individual is the person who may exercise the individual rights contained in the HIPAA Privacy Rule, including the right to request restrictions on uses and disclosures of

PHI for various purposes that may be carried out by an HIE (such as treatment, payment, and health care operations). 45 CFR 164.522(a) (requiring covered entities to permit “an individual” to request restrictions; providing that a covered entity is not required to agree to a restriction but if it does it must abide by the restrictions). It is possible that failing to provide unemancipated minors who receive services under G.S. 90-21.5 the opportunity to opt out could amount to a denial of the minor’s individual rights under HIPAA.

3. Failing to provide unemancipated minors who receive services under G.S. 90-21.5 the opportunity to opt out may increase the risk that information about a minor’s confidential treatment will be disclosed in violation of G.S. 90-21.4(b).

Under G.S. 90-21.4(b), the general rule is that a physician needs the minor’s permission to disclose information about services received under G.S. 90-21.5 to a parent, guardian, person standing in loco parentis, or legal custodian. There are two exceptions to this rule. First, the physician may disclose information to the parent, guardian, person standing in loco parentis, or legal custodian without the minor’s permission if the physician determines disclosure is essential to the life or health of the minor. Second, if the parent, guardian, person standing in loco parentis, or legal custodian contacts the physician and inquires about the treatment, information may be disclosed, provided such disclosure is permitted by any other confidentiality laws that apply to the specific information in question.

If a physician who retrieves information from the HIE about services provided under G.S. 90-21.5 is not aware that the services were provided under that law and that the minor is the “individual” with respect to the information, the physician may improperly disclose information about the services to the minor’s parent, guardian, person standing in loco parentis. It may be that this risk exists regardless of whether minors are provided an opportunity to opt out; however, providing minors the opportunity to opt the information out would seem to mitigate the risk.

Conclusion

By its own terms, the state HIE law appears to give unemancipated minors the right to opt out PHI related to care they receive under G.S. 90-21.5. While HIPAA does not address the issue as directly, it is clear that unemancipated minors should be treated as the “individual” when they are permitted by law to consent to health care and no other consent is required. This is a highly significant conclusion, as the term “individual” is used repeatedly throughout HIPAA to identify the appropriate person to take certain actions (such as authorizing the disclosure of information), and as the person who has particular rights (including the right to request restrictions on the use or disclosure of information).

Local health departments and other health care providers who serve unemancipated minors pursuant to G.S. 90-21.5 must ensure that they and their business associates have policies and procedures that protect the individual rights of these clients. The present limitations of HIE technology do not alter these obligations.